

**FIELD HEARING ON REAUTHORIZATION OF THE
TECHNOLOGY-RELATED ASSISTANCE FOR INDI-
VIDUALS WITH DISABILITIES ACT OF 1988**

HEARING

BEFORE THE

**SUBCOMMITTEE ON SELECT EDUCATION
AND CIVIL RIGHTS**

OF THE

**COMMITTEE ON EDUCATION AND LABOR
HOUSE OF REPRESENTATIVES**

ONE HUNDRED THIRD CONGRESS

FIRST SESSION

HEARING HELD IN RICHMOND, VA, APRIL 19, 1993

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**FIELD HEARING ON REAUTHORIZATION OF
THE TECHNOLOGY-RELATED ASSISTANCE
FOR INDIVIDUALS WITH DISABILITIES ACT
OF 1988**

MONDAY, APRIL 19, 1993

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON SELECT EDUCATION AND CIVIL RIGHTS,
COMMITTEE ON EDUCATION AND LABOR,
Richmond, VA.

The subcommittee met, pursuant to notice, at 10:03 a.m., Senate Room B, General Assembly Building, Virginia State Capital, Richmond, Virginia, Hon. Major R. Owens, Chairman, presiding.

Members present: Representatives Owens and Scott.

Staff present: Maria Cuprill, Wanser Green, Paul Seltman, Alan Lovesee, and Sally Lovejoy.

Chairman OWENS. The hearing of the Subcommittee on Select Education and Civil Rights is now in session. It is my pleasure to yield to Congressman Bobby Scott.

Mr. SCOTT. Thank you, Mr. Chairman, and it is certainly a pleasure to welcome you to Richmond.

It is indeed a pleasure to host the Subcommittee on Select Education and Civil Rights in the Third Congressional District and particularly a pleasure to call the meeting in a room that I worked in for the last 15 years.

It was in this very room, with the Rehabilitation and Social Services Committee, that many of us fought battles necessary to pass the Virginians with Disabilities Act, a statute which addresses many of the same issues that the Americans with Disabilities Act addresses.

I have a particular interest in the topic today, the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act.

Throughout my terms in the Virginia legislature, I worked to remove barriers to employment, and as I worked with many of the people in the room today to pass the Virginians with Disabilities Act, I learned that a small intervention can make a big difference.

In fact, 80 percent of the people with disabilities can work with accommodations, and those accommodations, in most circumstances, cost less than \$500.

Mr. Chairman, I am interested in hearing the witnesses' ideas regarding approaches for making more people with disabilities aware

of the services available both within their State and from the Federal Government to assist them.

I am also interested in recommendations of other technology-related services that States and the Federal Government need to provide to the disabled.

Mr. Chairman, I want to acknowledge one of the witnesses today. Kenneth Knorr is the director of the Virginia Assistive Technology System. It is a pleasure to be able to share Virginia's successes with this forum.

First, Mr. Chairman, I would like to yield very briefly to the Deputy Secretary of Health and Human Services, who will be welcoming us on behalf of the administration, Bobby Vassar.

Mr. VASSAR. Thank you, Congressman Scott, Mr. Chairman. It is a great pleasure for me this morning to welcome the select subcommittee on behalf of Governor Wilder and Secretary of Health and Human Resources Howard Collum.

We are very proud in Virginia to be a part of the select subcommittee's work, and we hope that, through our efforts, we can contribute to bringing about the productive enhancement to the lives of individuals with disabilities that we think the assistive technology momentum and effort has the potential for doing.

We hope that your stay here is both pleasant and productive, and if there is anything that we can do to assist, please don't hesitate to call on us, and we will be happy to provide any assistance we can.

Again, welcome.

Mr. SCOTT. Thank you, Mr. Vassar.

Mr. Chairman, thank you very much.

Chairman OWENS. Thank you very much, Mr. Secretary and Congressman Scott. We thank you very much for these very comfortable accommodations. We know that whenever it's related to Virginia, it will be high-quality.

I want to congratulate you, also, for sending a high-quality congressman, Bobby Scott, to Washington.

This is the first in a series of hearings regarding the reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988.

This law serves as a catalyst for systems change, encouraging States to survey policies and procedures that facilitate or impede the availability or provision of assistive technology devices and services.

Today, we will examine the progress made toward achieving implementation of statewide consumer-responsive programs. We will also look at models which enhance consumer independence and aid designated State agencies in effectuating systems change.

Currently, there are 42 State programs funded under this Act. These programs have developed innovative ways to empower consumers by providing them with knowledge about the latest services and technology available.

In some States, consumers can dial a toll-free number and obtain information about the devices they need: who manufactures the devices, who sells them and services them, and how to obtain funds to purchase these devices.

In addition, a number of consumers have been trained to make other consumers aware of the State's program services.

The Technology Act is a vital complement to the Americans with Disabilities Act. By working with individuals with disabilities to permanently improve their access to assistive devices and services, the Technology Act enables them to maximize their contributions to our Nation's workforce.

I want to thank Mr. Scott again for inviting the subcommittee here to Virginia to hold these hearings. The hearing process would not be complete without the input of those who are most affected at the local and State levels. We look forward to hearing their testimony this morning outlining their experiences and recommendations.

[The prepared statement of Hon. Major R. Owens follows:]

STATEMENT OF HON. MAJOR R. OWENS, A REPRESENTATIVE IN CONGRESS FROM THE
STATE OF NEW YORK

This is the first in a series of hearings regarding the reauthorization of the "Technology-Related Assistance for Individuals with Disabilities Act of 1988." This law serves as a catalyst for systems change, encouraging States to survey policies and procedures that facilitate or impede the availability or provision of assistive technology devices and services. Today, we will examine the progress made toward achieving implementation of statewide consumer-responsive programs. We will also look at models which enhance consumer independence and aid designated State agencies in effectuating systems change.

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I would also like to take this opportunity to extend a special welcome to Anastasia Somoza, a very special friend of President Clinton's.

Chairman OWENS. I would also like to take this opportunity to extend a special welcome to Anastasia Somoza, a very special friend of President Clinton.

STATEMENTS OF MARY SOMOZA AND ANASTASIA SOMOZA, NEW
YORK, NEW YORK

Ms. ANASTASIA SOMOZA. My name is Anastasia Somoza, and I am 9 years old. I live in New York City and go to school at PS 234 in Manhattan. I am in a third grade class in general education. I have a paraprofessional at school to assist me.

I have cerebral palsy and use a wheelchair. I also have a walker and a stander. I use a computer to help me with schoolwork and special software. I wear braces on my legs to help me keep them straight.

I like being in a regular class, because I now have lots of friends. As my friends live nearby, they come to my house for play dates and even sleep-overs.

At my old school, my friends lived too far away, and they never came for play dates. We could not go to their house either, because we did not have a car. All the kids at my old school were disabled, and it was hard for their parents to bring them to my house.

My best friend at school is called Natalie. She is not disabled. She helps me with lots of things, and she plays with me at recess time. I am the only one in my class who cannot walk, but that's okay. My friends push me around.

I have a twin sister who goes to the same school, but she is in a special class. She uses a computer to talk and a different computer to do her studies. She also uses a wheelchair and a stander. She is very, very smart, and I hope she can soon be in a regular class just like me.

Thank you.

[The prepared statement of Anastasia Somoza follows.]

STATEMENT OF ANASTASIA SOMOZA, NEW YORK, NEW YORK

My name is Anastasia Somoza and I am 9 years old. I live in New York City and go to school at PS 234 in Manhattan. I am in a third grade class in general education. I have a paraprofessional at school to assist me.

I have cerebral palsy and use a wheelchair. I also have a walker and a stander. I use a computer to help me with schoolwork and special software. I wear braces on my legs to help keep them straight.

I like being in a regular class because I now have lots of friends. As my friends live nearby, they come over to my house for play dates and even sleep-overs. At my old school, my friends lived too far away and they never came for play dates. We could not go to their house either, because we do not have a car. All the kids at my old school were disabled and it was hard for their parents to bring them to my house.

My best friend at school is called Natalie. She is not disabled. She helps me with lots of things, and she plays with me at recess time. I am the only one in my class who cannot walk but that's okay. My friends push me around.

I have a twin sister who goes to the same school, but she is in a special class. She uses a computer to talk, and a different computer to do her studies. She also uses a wheelchair and a stander. She is very very smart and I hope she can soon be in a regular class just like me. Thank you.

Chairman OWENS. Thank you, Anastasia.

Now we will hear from Mrs. Mary Somoza, the mother of Anastasia.

Mrs. MARY SOMOZA. Good morning. My name is Mary Somoza, and I am the mother of four children: my son, Oliver, is 10 years old; my twin daughters, Alba and Anastasia, are 9; and Gabriella, my youngest, is 5 years old.

My twin daughters are both disabled with cerebral palsy. Both girls are quadriplegics and use wheelchairs. Alba is more significantly involved than her sister. She cannot walk or use her hands.

My experience in obtaining assistive technology has been, to say the least, stressful. When my children were born, we had no medical insurance and initially had to pay for all their health-care needs until we were bankrupted.

It was then that we became eligible for medicaid, but the medicaid for the twins, through SSI, and the rest of the family were and remain uninsured. Due to the requirements of medicaid for us to remain low-income, we still are uninsured today.

In the early 1980s, acquiring technology through medicaid was a long procedure, and often by the time we would receive equipment, the child would have outgrown it. This is something that, for me as a parent, was the most terrible part of fighting for the technology.

We would go through all the paperwork, the hospitals find the technology that we need. A lot of times parents do not understand how to go about that and we rely on therapists who recommend it.

Then, by the time the paperwork goes through the system and by the time the system approves it and it comes back to us maybe a year or two or three years have gone by and the child has completely outgrown the technology.

This is still very common today in New York State, and it is very wasteful of State and Federal dollars.

I have many times received equipment that simply was not appropriate for my children, and I had no alternative but to keep it. This is what would happen when therapists ordered equipment for us without the possibility of trying it beforehand.

The therapists often would just see it in a catalog, assume it was the best thing for our children and order it, and by the time it came through and we had waited months and months to get it, they would figure out that it did not work for our children; but, we had to stay with the equipment and then try to apply for more equipment.

I felt very guilty about this waste of money. Invariably, I would then donate this equipment to one of the children's programs attended by my children.

One of the great problems about getting technology from medicaid is the very long wait from time of ordering to delivery. With growing children, this is a problem. It is also very frustrating for families when, after waiting many months for equipment, they find that it is either not right or too small.

Many times, in desperation, we were obliged to buy equipment urgently needed for our children because they could not afford to wait.

We, in turn, could not afford this equipment and had to go without other essentials in order to provide our children with what they needed so they could have it when they needed it.

Our first large expensive piece of equipment was a Light Talker communication device for Alba, Anastasia's twin sister. We applied to medicaid for this equipment, and we were turned down twice. We finally went to an impartial hearing and won the case.

However, even though we won, it took us 3 years, and that was 3 years of wasted time for my child, not to mention for me. I practically had to study the laws of the State to try to get my child's legal rights, and I think it is very unfair that we parents have to do that.

We have enough work just trying to raise our children without having to become experts in every aspect of State policy in order to obtain all the services our children require.

As a parent advocate in New York City, I have been successful, personally, in getting equipment for my children.

In New York City, for example, there are many, many families who do not have the abilities, nor the time nor the knowledge to go out and advocate for their children. Consequently, they do not get

the technology that we get. I spend 70 percent of my time trying to get these things for my children.

Most families cannot do that, and they really should not. That time we should be able to spend with our children, bringing up our children, which is hard enough, in the best of times, without having to fight for all the technology.

Wheelchairs are an area of great dilemma for me. With two growing children, unless their chairs can be provided in a timely fashion, it is very damaging both to the children and ultimately to the State.

My girls require custom-made inserts for the wheelchairs. This is a very costly device. By the time they are measured, the inserts and the chairs ordered by a hospital, approved by medicaid, and finally constructed by the vendor, my child has outgrown it.

Sometimes approvals take from 6 to 8 months, and yet, in New York State, procedures oblige medicaid to make a decision on durable medical equipment in 21 days. Most hospitals are unaware of this, and it is rarely implemented.

The other method of funding we have used for assistive technology is the Individual Education Plan in the public school system. This is for equipment that the child requires in the classroom to assist them in getting an appropriate education.

The Committee on Special Education sets up a review process which is very stressful for parents. More often than not, even when a prescription is provided for equipment, they make some excuse not to put it on the IEP.

Parents are totally overwhelmed and not knowledgeable of their children's rights. Every piece of equipment I have obtained for my children via their IEPs has been a battle for me.

I have always had to bring my Susan Goodman letter from the U.S. Department of Education to prove to them that this was my right, and that is how I got the equipment, because I said you have to give it to me. Most parents do not know that, so most parents do not get that.

The parent advocate system presently in place in New York is absolutely useless. The parent advocate has no access to the child's file before the meeting and, consequently, can give no oral input to the case.

I was a parent advocate, and I was trained by Advocates for Children in New York. I volunteered my time, my personal time, which I had very little of, to the school system to advocate, because I speak several languages, for Hispanic families and Haitian families who do not speak English and have a hard time fighting the system.

My school district never called me. One time a parent called me and said I am glad you are my advocate tomorrow morning. My name was on her paperwork. Nobody had informed me about it, and she would have gone to that meeting, and the school system would have said, oh, the advocate did not show up. So, they were using my name, but they never ever informed me.

So, the parent advocate system presently in the public school system in New York City does not work. They are generally rubber-stamp members of the team working in partnership with the CSE. I have always had more access working with outside non-

prompt advocates who are working on my side and not the Committee on Special Education.

I feel that parents are not properly informed of their rights or even of what is available out there to assist their children.

I won a TRAIID project scholarship in October 1992 to go to the Closing the Gap conference in Minnesota. I was astounded by the wealth of information out there available on technology that would have been of enormous assistance to my children.

I brought back as much literature as I could carry, and I distributed to all the parents I knew, the school systems, and the agencies.

I also went in the following week to a review process with my children with the list of technology—that has not made me the most favorite person in New York—and I've probably got the most extensive list of technology on my twins' IEP in the State of New York, but because I was an informed parent, only for that reason. It was equipment that had long been overdue and that my children desperately needed, and because I went to that conference, I found out it was out there and it was available. I went in with my Susan Goodman letter and I said you have got to give me this stuff.

They gave it to me, but unfortunately, that is not the case for most parents.

Knowing the TRAIID project operates a toll-free number in our State that we can call for information is of tremendous importance to parents. Receiving information through mailings, visiting the Regional Technology Center in New York City for information and guidance is a terrific asset to parents.

Also, in New York City—I can only speak about what I know—they have equipment that parents can go and look at and even try out before ordering the equipment, or if they do not have it actually onsite, we can look at it on a video tape or find out various different types of information.

A lot of times, unfortunately, therapists and people in hospitals work in collusion with certain people. I am sure there are wonderful people out there, but sometimes equipment is ordered for our children because the therapist has a good relationship with the vendor, and that does not help my child. So, it is terrific that parents like myself, who have an idea now, after several years in the system, can go to a TRAIID center where all that technology is on display, or go to a conference, look at it, try it out on our children before we go ahead. We can see what is best for our children, and we can be informed and knowledgeable in helping to choose equipment, very expensive equipment, taxpayer-dollar equipment.

We do not want to be wasteful with that, and this makes us more knowledgeable.

One of the great things about the TRAIID project in New York is their new trade-in program. Many times, when my children outgrow equipment, I have wondered what to do with it, and now I know.

It is also a great resource for parents who do not have Medicaid and yet cannot afford expensive equipment to get things they need quickly, cheaply, and without cost.

Right now, one of the fabulous pieces of equipment that I got on that IEP was a communication device for my child who cannot

speak, and I have another one at home which she had outgrown. It is a very expensive piece of equipment, and it will be valuable to some child or some adult.

I can now donate that piece of equipment to the TR Aid project. Somewhere out there in New York, there will be a child or an adult who can use it and who cannot afford it, and it would go to that person.

That is terrific for us, because believe it or not, we are not wasteful with the State's money. We want it to go back, because we know how hard it is to get in the first place.

There is a need for parents to be taught how to advocate for themselves. I had to do it the hard way, through trial and error. Now I know where to go for assistance from advocates, but most parents do not.

One of the things that always bothers me about the system is that so many parents out there, so many parents in neighborhoods, particularly in New York, that I am knowledgeable of, just do not know. If only they had that extra training, a little bit of help to empower them like I have become empowered—they want to do the best for their children—they could go out. They need to know, they need to learn, they need training. They need to know what is available.

I became a parent advocate because I was so mad. I could get things because I was empowering myself but then I saw all the other families who just could not do it.

The system is so complicated that, short of becoming a lawyer, many families cannot navigate it.

Just recently, I organized a meeting with the principal of my child's school. Because of all the publicity that my daughter received when she met with the President at the White House, we were getting very, very hostile reactions from my children's school.

Chairman OWENS. You were getting hostile reactions?

Mrs. MARY SOMOZA. Very hostile reactions, very hostile. On this piece of very expensive assistive technology that you see before you today, they carved PS 234 with a knife.

I mean we are trying to teach our children not to use graffiti, and here is the school system, on this enormously expensive piece of equipment, carving with a knife PS 234, because I had it written on my child's Individual Education Plan that she could bring it home from school to do her homework. It was almost like they were saying this is not yours, just in case you were thinking of stealing it or something of that nature. This was not necessary.

If they stamp the New York City Board of Education on it, that's fine, I have no problem with that, but to carve it on with a knife is absolutely not appropriate.

My children go to school every day, and the obstacles, questions, things that were happening at the school were amazing.

The White House called three times, and I told the person, the secretary, exactly what was happening. There will be intervention.

I cannot talk about it right now, but something very nice is going to happen which will be beneficial to our State. Because of all that publicity, I organized a meeting with the principal of the school to calm things down, to bring things back to a normal way of working. I found out 2 days before I went to the meeting that they were

going to bring in district administrators, the big guns, to gang up on me. So, I called Advocates for Children and I said I cannot go in there alone, because they are going to demolish me.

So, they sent in an advocate. The advocate, who for many years has been fighting for the rights of children in special education, was astonished at the level of hostility towards me in that room.

She said to me, in her own words, that had she not been present at the meeting and I had related it to her, she would not have believed me. This happens on a day-to-day basis. Parents are intimidated. They bring in teams of experts against us, and parents end up not getting their rights.

I was fortunate enough to be able to go in that day with an advocate, but this is what parents face every single day. Like the advocate said, in her own words, had she not been there, present, she would not have believed me about what happened.

The Technology Act has been of maximum importance to my family. It has given my children the chance to be really integrated in the community, attend school, and lead a normal life, like their brother and sister, who you saw in the photographs.

With the use of assistive technology, my children will have an equal chance to get an education and go on to take their place in the workforce. The Technology Act has given us the tools to assist our children in sharing in the American dream. We have the law on our side now to ensure that we get that fair chance.

I would like to thank you on behalf of my family and all the other families, particularly all the other families who cannot be here today. As you can see, we have a young advocate in training here today. I think she is going to be far more effective, as has already been proven.

I sincerely hope that when she grows up she will not have to fight as hard for her rights as we have to fight nowadays. I thank you all for allowing us to testify today.

Thank you.

[The prepared statement of Mary Somoza follows.]

STATEMENT OF MARY SOMOZA, NEW YORK, NEW YORK

My name is Mary Somoza and I am the mother of four children. My son Oliver is 10 years old, my twin daughters, Alba and Anastasia, are 9 and Gabriella, my youngest, is 5 years old. My twin daughters are both disabled with cerebral palsy. Both girls are quadriplegics and use wheelchairs. Alba is more significantly involved than her sister, she cannot talk or use her hands.

My experience in obtaining assistive technology has been, to say the least, stressful. When my children were born, we had no medical insurance and initially had to pay for all their health needs until we became bankrupt. It was then that we became eligible for medicaid, just for the twins, through SSI, and the rest of the family remain uninsured. Due to the requirements of medicaid for us to remain low income, we are still uninsured today.

In the early 1980s, acquiring technology through medicaid was a long procedure, and often by the time we would receive the equipment, the child would have outgrown it. I have many times received equipment that simply was not appropriate for my children, and I had no alternative but to keep it. This is what would happen when therapists ordered equipment for us without the possibility of trying it beforehand. Invariably I would then donate this equipment to one of the children's programs attended by my children.

One of the great problems about getting technology from medicaid was the very long wait from time of ordering to delivery. With growing children this is a problem, it is also very frustrating for families after waiting many months for equipment to come, to find that either it is not the right thing or it is too small. Many

times in desperation we would be obliged to buy equipment urgently needed for our children because they could not afford to wait. We in turn could not afford this equipment and had to go without other essentials in order to provide our children with what they needed so they could have it when they needed it.

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Wheelchairs are an area of great dilemma for me. With two growing children, unless their chairs can be provided in a timely fashion, it is very damaging both to the children and ultimately to the State. My girls require custom-made inserts for their wheelchairs. This is a very costly device. By the time they are measured, the inserts and the chairs ordered by a hospital, approved by medicaid and finally constructed by the vendor—my child has outgrown it. Sometimes approvals take from 6 to 8 months and yet in New York State procedures oblige medicaid to make a decision on durable medical equipment in 21 days. Most hospitals are unaware of this, and it is rarely implemented.

The other method of funding we have used for assistive technology is the Individual Education Plan in the public school system. This is for equipment that the child requires in the classroom to assist them to get an appropriate education. The Committee on Special Education sets up a review process which is very stressful for parents. More often than not, even when a prescription is provided for equipment, they make some excuse not to put it on the IEP.

Parents are totally overwhelmed and not knowledgeable of their children's rights. Every piece of equipment I have obtained for my children via their IEPs has been a battle for me. I have always had to bring my Susan Goodman letter from the U.S. Department of Education to "prove to them" that this was my right.

The parent advocate system presently in place in New York is useless. The parent advocate has no access to the child's file before the meeting and consequently can give no real input to the case.

They are generally "rubber-stamp" members of the team, working in partnership with the CSE. I have always had more success working with outside not-for-profit advocates who are working on my side—not the CSE's. I feel that parents are not properly informed of their rights or even of what is available out there to assist their children. I won a TRAIID Project scholarship in October of 1992 to go to the "Closing the Gap" conference in Minnesota. I was astounded by the wealth of information available there on technology that would be of enormous assistance to my children. I brought back as much literature as I could carry and distributed it to all the parents I knew, school systems and agencies.

Knowing the TRAIID Project operates a toll-free number in our State that we can call for information is of tremendous importance to parents. Receiving information through mailings, visiting the regional technology center in New York City for information and guidance is a terrific asset for us parents.

One of the great things about the TRAIID Project in New York is their new TRAIID-IN Program. Many times when my children outgrow equipment, I have wondered what to do with it. Now I know. It is also a great resource for parents who don't have medicaid and yet can't afford expensive equipment to get things they need quickly, cheaply, and without cost.

There is a need for parents to be taught how to advocate for themselves. I had to do it the hard way, through trial and error. Now I know where to go for assistance from advocates, but most parents do not. The system is so complicated that short of becoming a lawyer, not many families can navigate it. Just recently, I organized a meeting with the principal of my child's school. I went to the meeting with an advocate and am sincerely grateful that I did. The TRAIID Project was instrumental in arranging for my daughter Anastasia to meet with President Clinton at the Children's Town Meeting in Washington, DC. Due to the publicity that my Anastasia received after this meeting, the hostility leveled at me by the school made things very difficult. Afterwards, the advocate told me that had I related to her what happened at the meeting, the anger and hostility towards me in that room, she would not have believed me and would have considered me to be exaggerating.

The Technology Act has been of maximum importance to my family. It has given my children the chance to be really integrated in the community, attend school and

lead a normal life like their brother and sister. With the use of assistive technology, my children will have an equal chance to get an education and go on to take their place in the workforce. The Technology Act has given us the tools to assist our children in sharing in the American dream. We have the law on our side now to ensure that we have that fair chance. I would like to thank you on behalf of my family and all the other families who cannot be here today for extending this opportunity to our loved ones. As you can see, I have a young advocate in training with me today. I sincerely hope that as she grows she will not have to fight as hard as I have to obtain the things in life that are her right.

Respectfully submitted.

To whom it may concern:

Member of United Cerebral Palsy's Steering Council from 1985 to 1990.

Member of Manhattan Borough President's Advisory Committee for the Disabled (with Mr. David Dinkins as Borough President) from March 1989 to January 1990.

Member of Manhattan Borough President's Advisory Committee for the Disabled (Ruth Messinger as Borough President) from March 1990 to October 1992.

Elected Co-chair of Borough President's Committee September 1990.

Member of Subcommittee on Special Education of above committee.

In April 1990 I completed a training course with Advocates for Children to become a Parent Advocate at the Committee on Special Education.

I have worked with other parents in the public school system for the last few years (1989 to present) to implement sensitivity training as part of teacher education and curriculum.

Member of District 2 in Manhattan Special Education Parents Group.

Between March 1990 and July 1990 I completed a training session run by the Developmental Disabilities Planning Council (DDPC) in Albany to familiarize parents with the legislative process.

The DDPC appointed me Contact Person in New York City, and the NYC parents went on to form PACT (Parent Advocates Come Together) of which I became Chair.

PACT worked intensively on Family Support issues and worked with parents across the State to encourage the Governor to sign the Family Support Bill. This bill was signed into law in 1992.

In October 1990, I was invited by the U.S. Commissioner of Developmental Disabilities (Deborah McFadden) to Georgetown University in Washington, DC, as New York State Parent representative. I spoke about what NYS parents were doing to implement Family Support issues in our State.

Nineteen eighty six to present—volunteer on Westside Montessori School's Admissions Team.

Member of HRA's District Advisory Committee from 1987 to 1990.

Appointed by Governor Cuomo on October 8, 1991 as an Advisory to the Office of Mental Retardation and Developmental Disabilities. The term is for three years.

Member of Mayor Dinkins Advisory Committee for People with Disabilities.

Subcommittee member of Special Education Team about committee.

May 4, 1991—Speaker at United Cerebral Palsy's Nation Conference in Denver.

May 22, 1991—Testified before the United States House Subcommittee on Select Education and Civil Rights on behalf of UCPA at a hearing on the reauthorization of the Children with Disabilities Temporary Care Act.

I became a member of Lincoln Center's Advisory Board for the Disabled in 1990 and continue to be a member.

In September 1991 I was invited by the U.S. Commissioner for Developmental Disabilities to review Federal Grants in Washington, DC for a week.

In October 1991, I was the keynote speaker at UCP's annual conference in New Jersey. Topic of discussion—Parent Advocacy.

June 1992—Appointed by Governor Cuomo to the State Interagency Advisory Council for Early Intervention.

September 1992—Speaker at UCP's "education young fundraisers."

May 1992—Screening of the documentary "A Day at a Time" (a one hour documentary about my family—educational—what life is like in families with a disabled child or children).

October 1992—Won a grant from the NYS TRAIID Project to go to "Closing the Gap" Conference in Minnesota.

November 1992—Speaker at UCP's fundraiser breakfast for the Beauty Industry.

November 1992—Speaker at UCP's Blues in the Night fundraiser.

Member of the Technology Resource Center (TRAIID) in Manhattan (2nd year).

Member of the Advisory Board of the Child Development Center—Jewish Board of Family Services—October 1992.

February 15, 1993—Confirmed by NY State Senate Minority Leader Manfred Orhenstein for reappointment to the Early Intervention Council.

March 1993—Received "Parent Advocate of the Year" award for Cerebral Palsey of New Jersey.

Chairman OWENS. Thank you.

I was going to begin by apologizing for the awful behavior of the bureaucracy in the State of New York and the New York City School Board and say that at least you will no longer have that kind of treatment, because now you have Anastasia to fight with you as a result of the meeting she had with the President and the kind of attention it produced. However, then you went on, before I could make my remarks, to say that the meeting has produced hostility.

It is amazing that this should happen, and we certainly would like to pursue the situation further. You make a very strong case that no matter what we do with the program in terms of improving access to technology; the human factor—the need for advocacy and the need for advocates—is overwhelming.

You also indicated that you were astounded by the amount of information on technology which you encountered while you were attending a conference in Minnesota.

In light of that fact, do you think that we need some kind of national hookup for the transmission of information; a network by which information that is available anywhere in the country, in any one of the States, can be made available to parents in another State or location within the country?

Mrs. MARY SOMOZA. I think that parents are very territorial, and different States have different rules and regulations.

I cannot speak for the other States, but I know that in New York State we have a very good system where parents can call in and get information. I think if it becomes national, it becomes too distant for parents. Parents like to be more localized.

Chairman OWENS. I am speaking of a national system through which information would be transmitted. The information available in Minnesota could be transmitted to New York via some mechanism like computer, telecommunications, satellite.

Mrs. MARY SOMOZA. In New York State, we have a satellite system but it is all for our particular State. It is localized for our needs; for what is available in our State.

Chairman OWENS. A national network would allow you to know what is available anywhere in the country, and you could then question the officials of your State and ask why they don't have the same equipment available in New York. That is what we are talking about.

Would a national network like that be useful, or do you think we have now taken care of our deficiencies in New York?

Mrs. MARY SOMOZA. Absolutely not. Absolutely not.

Chairman OWENS. What is this center in New York that you mentioned where you can go to look at the equipment?

Mrs. MARY SOMOZA. Well, I think there are several places around the State. I know the New York City one, because that is where I live, and it is phenomenal.

Chairman OWENS. Is that maintained by the government?

Mrs. MARY SOMOZA. No. It is TRAUD.

Chairman OWENS. The industry maintains it?

Mrs. MARY SOMOZA. I do not know what that means.

Chairman OWENS. I mean the people who manufacture the equipment.

Mrs. MARY SOMOZA. No. No. It is the technology project that you chaps are reauthorizing—

Chairman OWENS. Funded by this bill.

Mrs. MARY SOMOZA. [continuing] funded by this bill that do that, and they have, like I say, all the equipment available.

My dream as a parent would be a type of Macy's, a department store where parents could go and see, on the third floor, wheelchairs; second floor, computer technology; fourth floor, whatever else, walkers, et cetera, et cetera. We could just go down to the department store and get everything that we need for children and persons with disabilities.

Chairman OWENS. At one point you did mention videos being available?

Mrs. MARY SOMOZA. Yes, absolutely.

Chairman OWENS. Is that from the same center?

Mrs. MARY SOMOZA. From the same centers. If the companies have videos available, you can view their equipment and how it functions on a video.

You can go with your own therapist and view this information and discuss various devices. We live with our children, Congressman Owens; we live with them every day, and we are the ones who end up having to put them into the devices.

Therapists and other professionals see therapeutically what is the best thing. We have to live with it. We have to have it in our homes. We have to carry it up two flights of stairs every day, which is what I have to do in New York.

So, I want some input on what is chosen for my child, because if my therapist orders a piece of equipment that is too difficult for me as the parent to use, it will sit in the corner, because it is too difficult for me to manipulate. I want to have input so I can say to the therapist, look, I live in a walk-up apartment, second-floor walk-up; I need something—a wheelchair that is lightweight, because I have to carry the wheelchair and my child up and down the stairs every day.

So, they have to cater to the needs of the families, as well, so that equipment is not wasted or not used at all.

So, I want to be able to go with my therapist to a technology center such as the one in New York, see what is available out there; if not physically on the floor, to see it via a videotape, to see information so I can know.

There are 15 different types of strollers that—when I cannot use a wheelchair, and I say, well, that is the one I want.

I saw this phenomenal piece of equipment that my child is standing in right now. I saw it at a conference—and it is not really marketed yet—and I just went out there and said, I have got to have one of these.

This piece of equipment that my child is using today will save the State, in the long run, an awful amount of money in unnecessary surgeries—because if my child is sitting down all day in a wheelchair, she will end up, over time, needing hip surgery, which

she had last year, for dislocated hips—all sorts of surgeries that could be prevented if she has assistive technology to stand instead of sit. I know there are a lot of congressmen out there who feel these items are luxuries. They are not luxuries to us, and they end up saving the State money.

Chairman OWENS. Speaking of money, you mentioned, as part of your unfortunate experiences, the fact that your family had to spend itself into bankruptcy buying equipment for the children before you were eligible for any government assistance.

Do you think the establishment of low-interest loan programs in the States would help consumers, like yourself, pay for assistive technologies? To what degree would that be useful?

Mrs. MARY SOMOZA. That is terrific. That was not available, or even if it was available, I did not know about it when my children were born. One of the reasons for bankruptcy was the medical bills.

We had no medical insurance, and the medical bills were astronomical. There were devices, such as bathing seats, special bathing seats, to go in the bath, because with very spastic children, you cannot just put them into a regular bath. They have to be held and secured.

There were bath seats. There were little special—like a baby would have a little rocking seat. We have to have special ones with straps everywhere to secure the child.

All of those things, in the early days, therapy equipment, we had to go out, and—basically, I sold everything I owned to get that. We knew that, even when we got medicaid—we got medicaid when my twins were a year old, by which time we had become bankrupted—it took so long, particularly in the early years. Parents are so overwhelmed when they have a child with a disability.

You do not know what is ahead. You do not know anything. Emotionally, you are extraordinarily vulnerable. You become financially bankrupt, as we did, because you have to get all this extra stuff.

In those early years, it is so important for families to get the maximum help with the least fighting and battles, because parents are too vulnerable at that stage in their child's life.

Lots of children are placed in institutions because, in the early days, the parents—there are so many things coming at them at one time.

Economic bankruptcy is sometimes not an option for parents. They do not want that, and they will place a child in an institution at great cost to the State and at horrendous cost to the family and the child because they cannot face all the things that confront them in the early days of having a child with a disability.

Chairman OWENS. We hope the legislation will help to avert those kinds of hardships.

You and your husband both are to be congratulated. Among the photos we have up here is a photo of the whole family, and you certainly ought to be congratulated for maintaining this beautiful family despite all of these hardships.

You are an exhibition of family values in the very best sense of the word, and I want to congratulate you.

Mrs. MARY SOMOZA. Thank you.

Chairman OWENS. I yield to Mr. Scott.

Mr. SCOTT. Thank you, Mr. Chairman.

Ms. Somoza, are you on medicaid now?

Mrs. MARY SOMOZA. The whole family is not on medicaid, just the twins. As I had mentioned, they get the medicaid because of the disability. The rest of the family, because we have to remain low-income to keep medicaid for the girls' needs, cannot afford insurance.

My two other children, my husband, and I have no medical insurance.

Mr. SCOTT. Does New York have—maybe this is more appropriate for someone else, but do you know if New York has a medically-needy category for medicaid?

Mrs. MARY SOMOZA. There are two types of—as far as I know—medicaid you can receive. If you are poverty-level, it would cover all the family, or if you get SSI, it is higher, and that is the category we come under.

The category we fall under is the SSI, and we are allowed to have a slightly higher income. We are not allowed to go above that. If we go above that, we lose their medical benefits.

So, the amount of money we are allowed to earn does not allow us to afford the high cost of medical insurance for the rest of the family.

Mr. SCOTT. This may not be related to this legislation, Mr. Chairman, but it seems to me that, as we are trying to get universal health coverage, we are obviously having a situation, in this case, where we are preventing people from obtaining their own health insurance. Maybe we will have to try to deal with that in a different forum.

You mentioned you got a Light Talker for your other daughter.

Mrs. MARY SOMOZA. Yes. We have a Light Talker which we are ready now to donate to the TRAIID project, because we got the new device, which is a liberator. For her level of ability right now, it is a better device.

The technology, as you know, advances, and she got this new device. Now we would like this other device, the Light Talker, to go on to some other person who can use it.

Mr. SCOTT. Can you explain how both of those work, the old one and the new one?

Mrs. MARY SOMOZA. They are for non-verbal persons. They are communication devices. My child, Alba is significantly disabled. She cannot use her hands. The one part of the body that she has control over is—she accesses these devices with a chin switch.

It is a scanning device. Right now, we are programming it for her, but the eventual goal is that she will be totally literate; that she will be able to use it fast enough to type in what she wants to say and the device will speak. That is how it is used. That is how it is used by persons with disabilities today who are literate.

Because of my battle with the school system in getting all the services together, she is on the road to literacy, but she is not totally literate yet. This new device is a much easier. I think people have to realize that our children—first of all, they are smart, they are bright.

They not only have to learn like any other regular schoolchild; they have to learn to use this sophisticated technology, which can

fatigue them. We have to look for the quickest and the easiest way for them to access this technology for it to be of use to them.

This new device that she is using is the latest thing. It is quicker, it is easier, and so, she is enthused. She was very frustrated with the old device, but it does not mean that it is no longer any good.

Another child may be in the beginning or may have more use of their hands or their body—that will be a phenomenal device for that child or that adult. But, for my child, the new one—because she is so significantly involved—facilitates her learning. It is quicker and it is easier, and it gives her more encouragement to use it.

Chairman OWENS. Thank you again, Mrs. Somoza. I want to thank both you and Anastasia. We hope that the surprise that you cannot share with us is going to move us a few steps further in terms of the relief of hardships for families like yours. We admire your courage and want to thank you again for appearing here today.

Mrs. MARY SOMOZA. Thank you very much.

Chairman OWENS. Our next panel consists of three witnesses: Mr. Kenneth Knorr, the Project Director of Virginia Assistive Technology Systems; Ms. Deborah Buck, the Project Manager, TRAIID Project, Albany, New York; Mrs. M. Nell Bailey, Project Director of RESNA Technical Assistance Project in Washington, DC. Please be seated.

We would like for all of the witnesses to understand that we have your written testimony. You may spend this time highlighting that testimony, and during the question period, you will have an opportunity to amplify any other point at that time.

We will begin with Mr. Kenneth Knorr.

STATEMENTS OF KENNETH KNORR, PROJECT DIRECTOR, VIRGINIA ASSISTIVE TECHNOLOGY SYSTEMS, RICHMOND, VIRGINIA; DEBORAH BUCK, PROJECT MANAGER, TRAIID PROJECT, ALBANY, NEW YORK; AND M. NELL BAILEY, PROJECT DIRECTOR, RESNA TECHNICAL ASSISTANCE PROJECT, WASHINGTON, DC

Mr. KNORR. Thank you.

The Virginia Assistive Technology System has completed 3 years of systems change activities. My comments are reflections based on experiences of implementing a consumer responsive statewide system.

My name is Ken Knorr, and it is pleasure to serve as director of this project and to work with the folks in Virginia like Anastasia and her mother, Mary.

I would like to address three things today: first of all, some of the accomplishments that we have realized in the State of Virginia; I would then like to touch on our future. Lastly, I would like to define what I consider to be the essential components of a systems change grant.

Our program, known as VATS, is administered by the Department of Rehabilitative Services and is guided by our Virginia Council on Assistive Technology. Our mission, as is Deborah's, is to

improve access to assistive technology for Virginians of all ages, of all disabilities.

The Department of Rehabilitative Services, as the lead agency, is fully committed to our program, as is evidenced by our Commissioner's direct involvement in the project design and ongoing supervision. The agency has also provided the project with much-needed additional resources.

We are very fortunate in Virginia in that a special Blue Ribbon Commission, which was chaired by the Lieutenant Governor, identified assistive technology as a priority area of need and mandated interagency collaboration and cooperation.

We believe we have an assistive technology systems model that works. We operate a number of different programs.

Our initial efforts focused on the establishment of the statewide council that I mentioned, a 25-member council that includes all of the major stakeholders, with a majority representation of people with disabilities. Our council consults, advises, and is fully integrated into all project activities.

During the first several years, we have initiated a number of policy initiatives. One of those was a statewide policy on assistive technology, where we pulled together the 11 State agencies that work with people with disabilities and together defined a single policy on assistive technology.

This resolution was endorsed by the Beyer Commission that I mentioned and was enacted by the legislature. It directs all of the State and local agencies who provide assistive technology to assure that clear and consistent policies and procedures are developed.

We have worked towards the establishment of a loan fund model program. We have been very fortunate in the national research that we have done, and NIDRR just recently extended their confidence to us by awarding a supplemental grant to further pursue model loan financing research for the country.

We have been able to establish a statewide information and referral system to increase the availability of information on assistive technology to all folks in Virginia.

We have a very extensive database consisting of 20,000 devices and services which is accessible by a variety of means, either by an 800 number directly over the telephone lines or coming in off the computer modem. We are receiving 200 contacts each month, the majority of them coming in off of the computer.

We have an equipment exchange bulletin board service. I was thinking about it when Mary was mentioning the Light Talker and how they were going to use that with other folks. We have a bulletin board service that links consumers to other consumers in the State of Virginia to make sure that this type of expensive equipment does not sit in people's closets.

We also just recently completed Virginia's first directory of funding alternatives that is ready now for widespread distribution.

We have set up four regional resource centers around the State, effective April of 1992. Each of these consists of a consortia of organizations to make sure we leverage the maximum amount of resources.

They have pulled together organizations such as Area Agencies on the Aging, Centers for Independent Living into their consortia.

We have had lots of public awareness in the last year and plan on being more intense in the next year. We have our own newsletter—some articles have appeared in all of the major newsletters around the State—television stories, presentations, demonstrations, and our own Annual Assistive Technology Conference.

In order to get resources to the communities, we have funded in the last several years 20 community-based grants totaling \$150,000; small seed grants to stimulate creativity and innovation.

These projects include such things as Consumer Advocacy Conferences that are actually run by consumers, and Ability Awareness Days. We are looking for those that are replicable and encourage collaboration around the State.

In the next year, we plan to maintain and systematize our current efforts. We are going to be looking at those things that address the next generation of needs across the Commonwealth.

With the groundwork laid for the development of assistive technologies across all of the State agencies I have mentioned, we are going to be providing technical assistance and support to them in the development of their own individual State policies.

We will be hosting a national satellite conference in September of 1993 to disseminate the information on the loan financing model so that all 42 projects can connect and select the type of model for loan financing they would like to introduce in their State.

We will be introducing a personnel preparation program for paraprofessionals to build the local capacity for delivering assistive technology services.

During this fourth year, we also expect that all of the rehabilitation offices and the Centers for Independent Living are going to be equipped to serve as information and referral satellites.

Funding activities are going to focus on implementing the models that we have identified for the country. Our resource centers will continue to provide activities like training, public awareness, information referral.

They will also be trying to identify some successful practices that they have had replicated across the State.

With the Rehabilitation Research and Training Center, we are going to set up a model for a Business Accommodation Response Team. The team is going to serve as the central point of contact for Virginia employers and respond to their job accommodation requests within 72 hours.

It is new; it is exciting; it will support lasting systems change. Not only will it address the needs of employers but it will also open up new job opportunities for people with disabilities.

The intent of the Assistive Technology Act is to promote systems change. I want to share with you what I consider to be the essential systems change activities or minimum components of any systems change grant.

First of all, an involved stakeholder. I mentioned the council that is working with us in all facets. That is essential.

Uniform statewide technology policies are critical, where you have all the State agencies working together.

An advocacy component, as you heard from Mary, is absolutely essential. We have a full-time person that works as a policy and funding analyst. Our resource centers also have advocates.

Regionally-based technology centers in order to try to respond to needs at the local level.

Personnel training, such as the personnel preparation training program thassistive technology we have planned.

Financial support to enable consumers to afford technology. That is what we have been hearing this morning.

An up-to-date service and product information system, such as our I&R system.

A consumer-to-consumer network such as the bulletin board service which allows consumers to empower one another.

Strategies to fund or promote innovations at the local level, such as the creative initiative grants that I have mentioned, and a minority outreach program. Virginia is very fortunate to have piloted the National RESNA TA's Project Reaching Out, getting out to minorities.

We understand that, for systems change to be fully effective and lasting, continuity must be there beyond the Federal funding. We recognize the need in Virginia to pursue alternative funding for long-term continuation of the statewide system beyond this Federal funding cycle.

We plan to conduct a feasibility study in this next year to determine the commitment to continue all of these major project components that I have outlined.

We will be looking for potential funding sources in partnerships with the private sector and other folks from the public sector.

We will be pulling together an Implementation Task Group. Our strategies will be refined, and we will be developing public relations material so we can go out and actually approach some potential funding sources to continue not only the creative initiatives that we were able to fund, but those many other activities at the local level that were very innovative that we were unable to fund.

I would like to provide you, in the next minute, some additional recommendations regarding reauthorization.

As other strategies are identified to sustain the Assistive Technology Act projects, Federal dollars will be necessary for the short run.

Funding authorities need to document and articulate indices of performance.

Projects should be funded based upon merit, and the projects should be held fully accountable for these dollars.

In order to stimulate creativity and flexibility, a competitive grant process should continue.

State projects should be expected to have an advocacy component and adhere to standards established for this purpose. However, these activities should be directed by the individual States themselves.

Lastly, given the diversity of approaches to the administration of these projects, each State should be allowed to choose what is best for them.

I believe that these last comments represent the consensus of the State directors that I have talked to as recently as several weeks ago up in Massachusetts.

Those of us in Virginia appreciate your willingness and your efforts to improve our country's assistive technology service delivery.

We would be glad to provide additional information and to work with you as you consider the specifics of reauthorization.

We fully support the purpose of the Assistive Technology Act and the flexibility provided to enable State-level innovation.

Thank you.

[The prepared statement of Kenneth Knorr follows.]

KEN KNORR, DIRECTOR

Introduction:

Virginia's Assistive Technology System (VATS) has completed three years of systems change activities. My comments are reflections based on experiences of implementing a consumer responsive statewide system. My name is Ken Knorr and it is my pleasure to serve as director of the project. I have now worked in the field of rehabilitation for over 20 years. I consider the last three years to be the most exciting and productive in my career. Technology itself generates a lot of excitement, but it is the Tech Act's commitment to consumer needs and the chance to implement systems change that motivated me to leave the Shenandoah Valley of Virginia for Richmond.

Background:

The Department of Rehabilitative Services (DRS) is the Commonwealth's National Institute on Disability and Rehabilitation Research (NIDRR) assistive technology (AT) grantee. The Virginia Assistive Technology System is administered by the Department and guided by the Virginia Council on Assistive Technology (VCAT). The mission of VATS is to improve access to assistive technology information, devices and services for Virginians of all ages and disabilities.

DRS was designated by our Governor as the lead agency responsible for implementing Virginia's assistive technology efforts under P.L. 100-407, the Technology-Related Assistance for Disabilities Act of 1988. The department chose to pursue the grant because it recognized that assistive technology would be critical to the implementation of the opportunities posed by the Americans with Disabilities Act.

DRS envisioned through this grant project:

- Including diverse public and private stakeholders
- Increasing accessibility and affordability of assistive technology
- Providing accurate user friendly information
- Stimulating individual and organizational innovation
- Developing consortia and networks to carry out and transcend the project to maintain services and consistent policies across organizational lines.

Efforts focused on system development that would transcend project timeframes and be supported by meaningful structures and products such as regional consortia and automated information and referral data base. In addition to increasing accessibility and affordability of assistive technology, stimulation of consumer, advocates and provider networks was a desired by-product. We have made progress in each of these areas.

This was the approach the Department chose in formulating application and implementation of the project. In order to develop a lasting consumer performance system, the Virginia Council on Assistive Technology was formed to have a meaningful role in project development and guidance. The project is staffed by DRS to promote inclusion and provide high quality products at each stage and to be open to recommendations and emerging opportunities.

DRS is fully committed to VATS as evidenced by the Commissioner's direct involvement in project design and ongoing supervision. DRS has provided the project with much needed resources such as financial management,

technical assistance for the design and implementation of the information and referral system, and careful selection of skilled staff. Products and activities have been expanded and expedited each year of our operation with the full support of people from every part of the organization.

In addition there has been support for systems change in Virginia through the efforts of a blue ribbon commission chaired by the Lieutenant Governor. The Commission comprehensively addressed the needs of persons with physical and sensory disabilities within the Commonwealth and quickly identified assistive technology as a priority area of need. Inter-agency collaboration and cooperation were mandated in this and other areas.

There has been a very receptive environment in Virginia. Paramount to the success of our project was the creation of a statewide council, comprised of diverse stakeholders who came together to focus on a common mission of assistive technology systems change. In addition to a statewide assistive technology council and its task groups, the system is available to Virginians through regional resource consortia, representatives from agencies concerned with disability related issues and advocates - all committed to providing access to technology-related devices and services.

The variety of programs include: Assistive Technology Resource Consortia (ATRC); community-based innovation grants; a statewide Information and Referral Network (I&R); an Equipment Exchange Bulletin Board System (EEBBS); assistive technology loan funding consultation services; policy development initiatives; public awareness activities; and local, regional, and national training/technical assistance efforts. These efforts respond to the

six primary purposes of the Technology-Related Assistance for Persons with Disabilities Act of 1988 (P.L. 100-407).

We believe we have an assistive technology systems model that works. Our project is based on careful design, implementation and review.

ACCOMPLISHMENTS THROUGH YEAR 3

Our initial efforts focused on improving capacity building through inter-organizational cooperation in the development of consumer-responsive policies and strategies. The establishment of the Virginia Council on Assistive Technology (VCAT) represents the foundation from which this and other goals are pursued. The VCAT is the advisory body, comprised of over 50% persons with disabilities or family members, essential to the development and implementation of the vision for VATS. The 25 member Council includes all of the major stakeholders to include consumers and family members, service providers, vendors, employers, advocates and agency representatives. The VCAT consults, advises, and is fully integrated into all Project activities. Individual Council members have participated on interview panels and in the formulation of goals and objectives, development of action plans and requests for proposals to respond to goals, selection of grantee recipients, and the implementation and evaluation of all activities. Members are active participants in the work of our three task groups that implement the systems change framework and workplans for VATS.

Policy Development Activities

Two major policy initiatives have been undertaken during Grant Years 2 and 3. These include 1) state compliance with Section 508 of the Rehabilitation Act, and 2) a statewide policy on assistive technology.

The development of a policy statement bringing Virginia into compliance with Section 508 ensures that public employees with disabilities have equal access to electronic equipment. Technical assistance will be provided by the Project and DRS staff to support this effort.

Statewide Policy on Assistive Technology

Representatives from 11 state agencies that provide services to persons with disabilities pursued a mutually authored statewide policy on assistive technology for legislative approval. A resolution was endorsed by the Beyer Commission and enacted by the legislature. The resolution directs state and local agencies who provide assistive technology to their clientele, to assure that clear and consistent assistive technology policies and procedures are developed which address: information and referral; types of devices and services provided through the agency; conditions of eligibility and extent of coverage; fiscal responsibilities; methods to inform individuals of their rights; consumer evaluations; provider and vendor standards; and the identification of unserved and underserved populations.

Loan Financing Model Development

During Year 2, VATS conducted preliminary national research on assistive technology loan financing models in operation across the country.

Alternatives currently under consideration in Virginia include a revolving loan

model and an interest buy-down model. Continued research is necessary to further develop these broad concepts and to identify other options.

During Year 3, VATS received a supplemental award from NIDRR to pursue national loan model research across both public and private loan programs that may have application to Tech Acts nationally. Loan programs that support disaster relief, student loan, and housing assistance are examples of possible models to be researched. The outcome of this research will be to develop loan financing models that address administrative, financing and oversight alternatives which states may employ to meet the individual circumstances of their states.

Information and Referral System

In response to significant issues identified through surveys and inputs from the Council for more information on assistive technology devices and services, an Information and Referral (I&R) System was established. The mission of the VATS Information and Referral (I&R) System is to increase the availability of information on assistive technology to all Virginians with disabilities. The I&R system seeks to bridge the gap between consumers and assistive technology-related devices and service providers. The I&R Task Group of the VCAT guides all of the activities of the I&R staff, ensuring that the system is consumer responsive and promotes system change. To that end, national databases on devices and services, such as ABLEDATA, have been integrated into a centralized statewide microcomputer database. Currently, the database contains approximately 20,000 devices and services.

The statewide I&R system is housed in Richmond and accessible by various means:

- a toll-free 800 number answered by an Information Specialist, allowing any person within Virginia to call in for assistance and access to information,
- a second 800 toll-free number allowing any person within Virginia with a computer and modem to directly connect with the system,
- walk-in sites at the four ATRCs and a public access workstation at the central VATS office.

The I&R system averages around 200 total contacts from consumers each month from the on-line database and the Information Specialists. The Information & Referral staff also provides technical assistance, presentations, and demonstrations upon request to consumers and providers.

Virginia's first directory of funding alternatives was recently completed and is ready for widespread distribution. The directory will be available in hard copy and on-line through our Information and Referral (I&R) database and will be accessible free of charge through our 1-800 number. The directory, the first of its kind in Virginia, informs consumers of what funding resources and services are available and how to access them. It concisely overviews the assistance available from government agencies, independent living centers, civic and service organizations and private insurance companies. To aid potential recipients in their efforts to obtain assistance, detailed guidance on the application and appeals processes is provided.

VATS recognized that no single, coordinated point of contact for individuals needing to exchange assistive technology devices, information and ideas existed in Virginia. Many organizations such as hospitals, non-profits, and

independent living centers serve as local access points for similar services. Each of these contacts has welcomed the prospect of VATS as a point of coordination for the posting and maintaining of the equipment exchange information. VATS has chosen to address this need through the development of a user-friendly Equipment Exchange Bulletin Board System (EEBBS), and a mentorship/consumer consultation program that is to be implemented at the regional level. The information relating to assistive technology devices will include equipment for sale, rental and giveaway.

The EEBBS runs on a stand-alone microcomputer and is provided in two formats: 1) an 800 toll-free voice number connected to the VATS I&R specialist to take equipment exchange inquiries, and 2) direct computer access. The EEBBS is designed to allow consumers the ability to leave messages and electronic mail to other consumers. The purpose is to link consumers seeking used devices with consumers who want to sell or donate their used devices. This simulated "trading post" empowers consumers and at the same time, removes the burden of having to use a state agency as an arbitrator of equipment exchange agreements.

Assistive Technology Resource Consortia

In the knowledge that a state the size of Virginia could not be effectively reached from a single office in Richmond, four regional technology-related assistance centers were envisioned as part of Virginia's Assistive Technology System. These regional resources would carry out many of the same functions as the central office -- training, public awareness, Information and Referral -- in addition to facilitating Assistive Technology

demonstration opportunities and responding to their respective region's specific needs. Central resources were provided to the ATRCs at the onset to enable them to initiate services to respond to the needs of their region immediately.

A Request For Proposal for the establishment of the ATRCs was developed with inputs from the VCAT, and distributed to 450 individuals and organizations. In an attempt to leverage maximum resources and to encourage coalition building and collaboration, the RFP insisted that a consortia of organizations and entities be established prior to submission. The RFP also requested that the proposal include a section on plans for continuing the consortia beyond the federal funding cycle. Seven proposals were received from around the state and four consortia were selected with the assistance of review panels comprised of AT users, Council members, vendors and service providers. The four ATRCs were funded in April, 1992 and announced in simultaneous press conferences.

Each ATRC consists of a consortium of organizations, with one designated as the lead entity for each ATRC. Three of the ATRCs have a university for the lead entity; the fourth has a State rehabilitation center for its lead entity, and works closely with another State university. All ATRCs involve people with disabilities as advisors and/or staff roles. Consortia members include multiple sites within the regions such as Area Agencies on Aging, advocacy groups, Center for Independent Living, area rehabilitation offices, rehabilitation centers, Human Resources Information and Referral Systems, the Cerebral Palsy Center, state agencies and others.

Training and Public Awareness

The Public Awareness and Community Integration Task Force of the VCAT guides the implementation of public awareness activities. VATS publishes an eight page newsletter, Connections, that is disseminated to 8,000 people. A number of articles about different aspects of VATS and ATRC operations appear in a variety of publications throughout the year. Television stories have been aired in an attempt to generate public awareness of assistive technology. In addition VATS and ATRC staff gave myriad presentations and I&R demonstrations and took part in exhibit opportunities in conferences and tech expositions around Virginia.

VATS contracted with the Rehabilitation Research and Training Center (RRTC) in the first year of the project to provide training and technical assistance. As with other activities, initial efforts focused on developing a system that could be transferred to the communities. Capacity building at the local level was seen as vital to continuance of activities initiated by the systems change grant. VATS and select other DRS staff were provided with training to sharpen their facilitation skills. Training curriculums were developed for three specific audiences: consumers, service providers and employers. The sessions were developed as prototypes with the expectation that the ATRCs would tailor the curriculum for their own audiences and deliver similar trainings in their regions.

VATS has held two Annual Assistive Technology Conferences, and we are planning for our third this May which we anticipate will be attended by 300 individuals. Best practices in Virginia and across the nation are highlighted at the conferences. Participants representing all of the major stakeholders

are given an opportunity to define their needs and to collaborate with others with an investment in enhancing the assistive technology system in Virginia. In September, 1992, a panel of consumer experts was convened to identify indicators of consumer responsiveness. The objective of this study is to obtain basic information from which to implement consumer-responsive activities. This study will be incorporated into the overall evaluation design.

Creative Initiative Grants

The Virginia Assistive Technology System funded twenty Creative Initiative Proposals totaling \$150,000 dollars during Years 2 and 3. The purposes of the grant program is to 1) promote the independence, productivity, and quality of life of persons of all ages with disabilities through improved access of underserved Virginians with disabilities to assistive technology products, services and information; and 2) provide small seed money grants to stimulate innovation and activate parts of the network.

Review panels, comprised of consumers, Council members, various agency staff, and other stakeholders selected the final recipients. Activities funded have ranged from the Richmond Cerebral Palsy Center's Consumer Advocacy Conference to the Center for Independence's Ability Awareness Day. The consumer advocacy conference was planned by consumers and attended by over 100 individuals with disabilities and their families. The theme of the conference was empowerment and self-advocacy. The Ability Awareness Day event was quite successful. Over 40 service providers and vendors were represented and many persons from the Southwest part of the state attended.

The creative initiative grant program supports systems change by promoting innovation and creativity in the development and delivery of assistive technology products and services. The grant support innovation of people who are typically not grant writers. Many of these ventures are replicable and encourage collaboration among agencies and organizations, thus encouraging an expansion of the network designed to improve access to assistive technology.

Traditionally projects have been funded for three years. As you have heard, we have only been able to scratch the surface of implementation because of the wide breadth and scope of assistive technology systems. In our mission to be both consumer responsive and collaborative we have tried to involve users and professionals in all phases of our operations. Our work is not done and we have made plans for forth and fifth year of systems change events.

PROPOSED ACTIVITIES FOR YEAR 4

The proposed activities to be accomplished in VATS Year 4 are intended to maintain and systematize current efforts. These efforts will position VATS to address the next generation of needs across the Commonwealth as we identify practical applications, move towards lasting change and increased awareness. These areas include initiatives such as statewide capacity building and integrating assistive technology with the Americans with Disabilities Act implementation through coordinated job accommodation.

Policy Development

With the groundwork laid for assistive technology policies to be developed across state agencies, VATS will be providing technical assistance and support in the development of those policies. Section 508 implementation will be provided in a similar fashion with a technical assistance team supporting state agencies in their implementation compliance with the policy.

Training and Public Awareness

During the next year, VATS will be putting the products developed in the first years in the hands of the practitioners and consumers. A national satellite teleconference in September 1993 will be coordinated to disseminate information on loan financing models to Technology Projects. Training materials will accompany this activity. VATS will hold its Fourth Annual Conference on Assistive Technology.

The development of a personnel preparation program for para-professional rehabilitation technologists will also occur. The objective of this program is to build local capacity to deliver assistive technology services. Our intent is to replicate this program to the state's community colleges.

DRS counselor and other service providers will receive training on using VATS I&R system. Having set the stage we are moving toward lasting change by bringing the project knowledge to the desks of persons who work directly with consumers. During Year 4 it is expected that all rehabilitation offices and CILs will be equipped to serve as I&R satellites. This will result in more person to person I&R involvement. Public awareness

activities will emphasize the electronic bulletin board services, newsletters, poster development, media and major outreach endeavors aimed at increasing awareness and sensitivity to people with disabilities who use assistive technology devices in their daily lives.

Information and Referral

The I&R staff will continually update the I&R System's national databases, such as ABLEDATA and IBM Products and Services, as new versions of the data are released. Along with maintaining data, the I&R staff will seek new databases on devices, databases considered highly accurate and relevant in the rehabilitation community to add to the on-line system. We will continue customizing and tracking information to make it more relevant to the needs of Virginia's consumers and practitioners. An emphasis will be placed on networking with service organizations throughout the Commonwealth in building a statewide database on Virginia service providers.

Funding Development

Funding activities for Year 4 will focus on the exploration of loan fund implementation. Having now researched financial models for a loan fund (i.e., revolving loan fund, loan guarantees, rate buy-downs, and hybrids thereof), VATS staff will be evaluating strategies for implementing the various models. Implementation of a loan fund will ultimately require a public/private partnership which effectively balances the interests of public agencies, the banking community, and consumers. Fourth year efforts will therefore focus on state authority, financial oversight, use of a non-profit/foundation to provide the consumer support component, and development of a banking partnership.

Electronic Bulletin Board Exchange

Having recently developed the capacity to offer the electronic bulletin board as a mechanism for connecting consumers with various types of information, several initiatives are proposed for Year 4. These involve a consumer to consumer equipment exchange component, a consumer consultative network that will connect consumers with their peers, and a consumer to service provider exchange alternative. Each are intended to build on consumer empowerment and responsiveness in the provision of information, and acquisition of assistive technology. This activity directly deals with the problem that lots of technology winds up in closets, when there are people who can use it. The service will be widely publicized to increase consumer impact including access to people without the use of computers.

Assistive Technology Resource Consortia

Each of the existing ATRCs will continue operation through Year 4 providing training, public awareness, and information and referral. Each will pursue their own select areas of specialization in program development and evaluation such as curriculum development and minority outreach. Successful practices will be disseminated for possible replication by the other ATRCs. These consortia are one of the vehicles for leveraging resources expanding the systems work. They will be expected to develop resources for continuity.

Business Response Teams

A model for a Business Accommodation Response Team (BART) will be developed and piloted during the Fourth Project Year. The primary objective

of BART is to have a central point of contact for Virginia employers and respond to their job accommodation requests within 72 hours. Teams will be comprised of consultants including job placement specialists, rehabilitation engineers, employment specialists, occupational and physical therapists, and rehabilitation counselors. This activity is new and exciting and will support lasting systems change. It addresses the needs of employers and opens new job opportunities for people with disabilities.

SYSTEMS CHANGE ACTIVITIES

As the intent of the Tech Act is to promote systems change activities, let me share with you what we in Virginia consider to be some of the essential systems change activities. The following are considered to be the minimum components and approaches of a systems change grant.

- 1. An involved stakeholder.** The Virginia Council on Assistive Technology guides all of the activities of VATS. Members represent each of the stakeholders with an investment in systems change in Virginia. The stakeholders themselves bring together consumers, practitioners and agencies committed to that end.
- 2. Uniform statewide assistive technology policies.** Virginia recently passed a resolution directing state and local agencies who provide assistive technology to their clientele, to assure that clear and consistent assistive technology policies and procedures are developed. The policies are to be consistent across agencies and are intended to remove barriers and provide for consumer choice.

- 3. An advocacy component.** VATS has a full time person designated to provide technical assistance to current and potential assistive technology users and families to assist them in advocacy efforts to obtain assistive technology. The ATRCs also provide technical assistance in advocacy.
- 4. Regionally based technology centers.** Four Assistive Technology Resource Consortia have been established in Virginia, designed to respond to the needs of consumers at the local level, including the introduction of a consumer consultative network that will pair consumers with their peers in an attempt to help them negotiate through the various systems.
- 5. Personnel training.** A Personnel Preparation Training Program designed to increase the numbers of individuals who can perform para-professional rehabilitation technology services to Virginians with disabilities is proposed for Year 4. The program will build local capacity to deliver assistive technology services and will adhere to the principles of systems change by helping to expand a responsive service delivery mechanism.
- 6. Financial support to enable consumers to afford technology.** VATS is committed to the development of methods to assist consumers in financial access to technology. A Supplemental Award from NIDRR has been received to expand on our research efforts and identify various loan alternatives for other states.
- 7. Up-to-date service and product information.** VATS has developed one of the most extensive on-line database of

services, products and funding sources available to persons with disabilities.

8. **A consumer to consumer network.** VATS recently introduced an EEBBS to link consumers seeking used devices with consumers who want to sell or donate their used devices, thus empowering consumers and removing the burden of having to use a state agency as an arbitrator of equipment exchange agreements.
9. **Policies ensuring compliance with Section 508.** The development of a policy statement bringing Virginia into compliance with Section 508, represents the first statewide policy in Virginia providing public employees with disabilities equal access to electronic equipment.
10. **Strategies to fund or promote innovation.** VATS has committed \$150,000 in the last two years to stimulate creative assistive technology initiatives.
11. **A minority outreach program.** VATS co-sponsored the national pilot testing of RESNA TA's Project Reaching Out, designed to develop culturally sensitive materials about assistive technology for minority groups and service providers who work with minority populations.

RESOURCE DEVELOPMENT ACTIVITIES

For systems change to be fully effective and lasting, continuity must be there beyond federal funding. VATS recognizes the need to pursue alternative funding for long term continuation of the statewide system

beyond the federal funding cycle. VATS approached RESNA for a technical assistance visit to identify language that could be incorporated into a request for proposal that would identify someone to coordinate this activity. In November 1992, Paul Hearne, Director of the Dole Foundation spent several days with VATS staff brainstorming possible approaches. The following activities may be included:

1. Conduct a feasibility study and determine commitment to continue the major Project components to include: ATRCs, capitalization of the loan fund, I&R system, Creative Initiative Grants. Interviews will be conducted with legislators, consumers, private sector and public officials.
2. Identification of potential funding sources specific to program components with strategies to solicit resources in conjunction with the purposes of each component.
3. Interpretation/analysis of interviews to determine amount of support in terms of resources (dollars, staff, equipment).
4. Recommend strategies and realistic timeframes for accomplishment of goals.

After completion of the study an implementation task group will be formed. Strategies will be refined and public relations materials developed for approaching potential sources.

Additional recommendations regarding state Technology Project continuation include:

1. As other strategies are identified to sustain the Tech Act Projects, federal dollars will be necessary for the short run.
2. Funding authorities need to document and articulate indices of performance.

3. Projects should be funded based upon merit and held accountable for their dollars.
4. In order to stimulate creativity and flexibility a competitive grant process should continue.
5. State projects should be expected to have an advocacy component and adhere to standards established for this purpose. However, these activities should be self-directed by the individual state project.
6. Given the diversity of approaches to the administration of these projects, each state should be allowed to choose what is best for them.

Those of us in Virginia appreciate your willingness and efforts to improve our country's assistive technology service delivery. We would be glad to provide additional information and to work with you as you consider the specifics of reauthorization. We fully support the purposes of the Tech Act and the flexibility provided to enable state level innovation.

Chairman OWENS. Thank you.

Ms. Deborah Buck, TRAIID.

Ms. BUCK. Good morning. My oral remarks are excerpted from my lengthy written testimony, which is before you. Later in my testimony, I refer to several of the project highlights, and you can easily reference that. It is on the back of the title page of the written testimony.

I am Deborah Buck. I am Project Manager of the New York State TRAIID Project. New York State is, to date, the largest State funded under the Assistive Technology Act. The TRAIID project in New York is administered by the New York State Office of Advocate for the Disabled.

The State Advocate, Frances Berko, is in a cabinet-level position, and the office is located, organizationally, within the Executive Department. The OAD uses a systems approach to advocacy.

Being situated in a systems advocacy agency has afforded the project a unique opportunity to understand the strategies necessary for collaboration and the practical realities of the time involved in convening key players, raising awareness, and negotiating arrangements yielding systems change.

To be effective, the systems advocacy approach requires that (1) OAD's visibility on a given issue be minimized, (2) any public display of militancy be avoided, and (3) recognition for the changes that occur go to the State agency that actually initiated the resulting change.

According to the 1990 U.S. Census, New York has 17.9 million residents, making it the second most populated State in the Nation. Approximately 2.5 New Yorkers, a number greater than or equal to the entire populations of 20 States, are known to have a disability.

New York City, the most populous city in the Nation, has 7.5 million residents. Over 2.2 million persons are of Hispanic origin; over 2.8 million are African-Americans; almost 700,000 are Asian and Pacific Islanders; and over 600,000 are Native Americans.

Language and cultural differences often pose barriers to both delivering—in a culturally component manner—and obtaining appropriate assistive technology devices and services.

New York's upstate rural aspects counterpoint its downstate urban aspects. Despite popular misperception, agriculture is the number one industry in New York.

Persons with disabilities residing in rural counties face different barriers to accessing assistive technology, including inadequate information about service availability, non-existent local service providers, and the lack of accessible transportation to travel to services in another nearby county.

In attempting to effect systems change, the TRAIID Project has chosen to implement a two-prong approach generating input and initiatives from both the top down and the bottom up.

Project staff: The three project staff at the central office level maintain responsibility for systems change through intervention in administrative, legislative, and regulatory activities.

Local outreach is achieved through regional TRAIID centers which promote grassroots involvements and access for consumers.

The intent of these activities is to increase both knowledge and empowerment, since an informed consumer can better self-advocate to bring about desired change. Mrs. Somoza and Anastasia are perfect examples of that.

The TRAIID Project, thus far, has established five regional technology centers. This year, we'll see the development of another center in the north county of our State. Even with six centers funded, many residents of the State still have to travel long distances to reach an RTC.

Centers offer device demonstrations, information and referral to local resources, education, training, and advocacy services.

The office also maintains a bulletin board service, as well, and offers interconnectivity for their technology centers as well as linkages to national networks, such as ABLEDATA, AppleLink, et cetera.

During the last 9 months, the RTCs have provided 1,253 product demonstrations to 448 persons with disabilities, 382 family members, 376 providers, and 47 employers.

Since receipt of the initial grant in 1990, the OAD instituted procedures to expand access to AT information and track requests. The office has maintained an information and referral service for about the past 10 years. With receipt of the grant, we added on to that information service and approached from a holistic viewpoint.

Since October 1992, a 6-month period, the OAD has received 8,432 information and referral calls. Of that total, 1,220, or 14½ percent, have been AT-related.

TRAID-IN, an equipment exchange service also instituted in October 1992, has generated phenomenal interest. In the month of October 1992, we had 10 TRAIID-IN calls. We are currently receiving 10 to 12 calls per day about the service.

The State has made significant progress under its Title I development grant in articulating a common vision for future access that endorses consumer involvement as equal partners, supports the State's economic and human resource commitment, and promotes prudent planning for the use of limited fiscal resources.

After recognizing the need for collaboration in the development of policy and planning for future access to assistive technology, commissioners from the key State agencies made a joint commitment to form an interagency partnership by an assistive technology.

Henceforth, the interagency partnership, in collaboration with the TRAIID Advisory Board, will provide the forum for discussing many of the issues involved in negotiating policy and program revisions necessary to implement a consumer-driven statewide system with a life beyond the Assistive Technology Act.

The project's successes in the last 9 months include sponsoring a series of five regional workshops.

The Department of Health recently released guidelines on—medicaid guidelines for funding of augmentative alternative communication at which more than 200 persons, providers, consumers, and parents attended.

We have sponsored a series of statewide planning meetings of individuals with disabilities, family members, providers, and State

agencies to develop a long-range plan to improve and expand access to assistive technology devices and services.

When Mary spoke and shared her vision with you of a Macy's system, that is very reflective of the actual vision that came out of this long-term planning process. Everyone, be it the person with a disability, the provider, or the State agency head, very much endorsed the concept of access for everyone.

We have developed a series of brochures on funding of assistive technology. The demand greatly exceeded expectations. With limiting access to brochures to 25 per person, we depleted an initial supply of 5,000 in a 5-day period.

We participated on the Region Select Commission on Disability Technology Committee to develop recommendations to the State Board of Regents, particularly as it relates to provision of assistive technology to promote inclusion, integration, et cetera.

We participated as a member of the Department of Health Task Force on early intervention reimbursement methodology under Part H and reviewed and recommended language to be included that addresses assistive technology devices and services.

We're currently participating on the Governor's Telecommunications Exchange, which has been directed to formulate a statewide policy regarding telecommunications.

Some of the problems that we have encountered are the lack of publication of New York State IDEA regulations, the need to await final Federal regulations for the reauthorization of the Rehabilitation Act, the lack of a consistent philosophy in existing disability statutes.

The attempt to promote consistent philosophy has been demonstrated by the passage of the ADA and with the reauthorization of the Rehabilitation Act, promoting full inclusion of people with disabilities, and we feel strongly that this approach needs to be reflected in all the disability statutes.

Other problems include the need to force-fit funding of assistive technology devices and services into existing eligibility criteria and the need to enhance public and private partnerships to develop creative funding strategies.

Persons skeptical or reluctant to effect systems change can validly state that the Assistive Technology Act is currently time-limited. A strong argument for continuation of the State grants is the preservation of the initiative to set the stage for implementation of 21st century strategies regardless of existing vested interests.

Although Title I development projects focus primarily on systems change, the need to support individual case advocacy for consumers and their family members must be recognized.

Any statutory emphasis to funding advocacy services in the reauthorization should ensure supplemental funding and foster flexibility to reflect collaborative initiatives that could work best in each State.

Such flexibility will not endanger advocacy efforts and initiatives that have already proven to be effective and consumer-responsive.

Since its inception, the New York Project has placed a great deal of emphasis on capacity building by promoting systems change.

Although New York is a State perceived to be rich in resources, the severe fiscal crisis experienced in the last few years has made it a challenge to access the limited resources actually available.

The implementation of the TRAIID Project has enabled New York citizens to become more aware of the potential assistive technology. Conversely, the desired outcome for increased consumer demand has conversely amplified the impact of our tight fiscal climate.

New York does not perceive increased Title I funding as the panacea. The per capita award, however, for all of New York State was markedly less than that received by other States.

The grant awarded to a neighboring State amounted to one dollar per resident, whereas New York's second-year grant equated to three cents per capita.

The demand on Title I States to not only effect systems change but to also provide a range of direct AT services has posed a significant strain on the ability to accommodate the differential volume of requests based on individual State characteristics.

For example, one of the Title I States, also receiving a larger grant award than the State of New York, responded to slightly over 1,000 assistive technology-related information and referral calls in a 12-month period, whereas New York State has responded to almost two-and-a-half times that amount in a comparable period.

An equipment exchange program operated by another Title I recipient yields an average of 39 calls per month. This program has been operating for a period of 5 years and provides services to multiple States.

In contrast, operating since October 1992, a 6-month period, New York alone has over 300 items currently on its exchange, and we are responding to an average of 10 to 12 calls per day.

We recently did a public outreach about the project, and there are days we are getting 20 to 25 calls per day.

The TRAIID Project and the agencies represented on the Governor's Human Services Sub-Cabinet are committed to building on existing inroads for changes affecting all New Yorkers with disabilities.

As decisions are made concerning the criteria for future funding allocations and continuation decisions, we request consideration of a more equitable approach to determining grant awards.

Factors that relate to the demographic diversity, such as a State's geography, population size, multilingual and cultural sensitivity, and realistic costs of effecting the scope of changes to impact expanded consumer options in a State should drive the award decisions.

Thank you very much for the opportunity to appear before you today.

[The prepared statement of Deborah Buck follows.]

Committee on Education and Labor
Subcommittee on Select Education and Civil Rights
Public Hearing/Reauthorization of the
Technology Related Assistance for Individuals
with Disabilities Act of 1988
P.L. 100-407
April 19, 1993

New York State Office of Advocate for the Disabled
TRAID Project
Frances G. Berko, State Advocate
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PROJECT HIGHLIGHTS

- Provided information and referral services to 14,872 individuals statewide, 2,434 or 16% of the calls were assistive technology related.
- 448 individuals with disabilities, 382 family members, 376 service providers, and 47 employers visited the regional technology demonstration centers for hands-on try out of assistive technology devices.
- Established the TRAIID-IN Statewide Equipment Exchange Service. A press release issued from the Governor's Office resulted in a 600% increase in participation. Calls for TRAIID-IN currently average 50 per month.
- Over 23,000 individuals statewide attended TRAIID awareness activities.
- Sponsored a series of five regional workshops on "Medicaid Guidelines for Funding of Augmentative/Alternative Communication Systems in NYS", at which a total of 200 persons attended.
- Awarded a total of \$294,000 to 7 regional technology sites across NYS where individuals can access TRAIID services.
- Sponsored a series of statewide meetings of individuals with disabilities, family members, service providers and state agencies to develop a long range plan to improve and expand access to assistive technology devices and services. The meeting served as a catalyst resulting in the formation of The Interagency Partnership on Assistive Technology.
- Disseminated a Needs Survey to 1,621 consumers and 1,193 service providers throughout NYS. (available in alternative formats and Spanish)
- Developed brochures on "Medicaid Funding", and "Public and Private Funding Sources". To date, brochures have been disseminated to 8,587 individuals. Brochures on funding assistive technology through the Education System; Vocational Services; and using Plan to Achieve Self Support (SS1) have been drafted and are under review.
- Participated on the Regents Select Commission on Disability, Technology Committee, to develop recommendations to the State Board of Regents to eliminate barriers and improve access to services.
- Participated as a member of the Department of Health Task Force on Early Intervention Reimbursement Methodology, and reviewed and recommended language to be included that addresses assistive technology devices.
- Participating on the Governor's Telecommunication Exchange which has been directed to formulate NYS policy on telecommunications.

Represents Activities from April, 1992 to December, 1992

I'm Deborah Buck, Project Manager of the New York TRAIID Project. New York State is, to date, the largest state funded under the Tech Act.

The TRAIID Project in New York State is administered by the New York State Office of Advocate for the Disabled. The State Advocate, Frances G. Berko, is in a cabinet level position and the office is located organizationally within the Executive Department. The State Advocate is a member of numerous Statewide Advisory Boards. The OAD operates in a systems approach to Advocacy Services.

To be effective, this systems advocacy approach requires that: (1) OAD's visibility on a given issue be minimized; (2) any public display of militancy be avoided; and (3) recognition for the changes that result go to the state agency that initiated the change. The present primary focus of OAD currently is on three interrelated topics: universal access to assistive technology; statewide implementation, not enforcement, of ADA; and universal and independent access to information concerning available program services and supports by persons with disabilities and their parents to implement and ensure complete freedom of choice.

Life within the 47,377 square miles of New York State is characterized by kaleidoscopic contrasts; cosmopolitan or colloquial; rural/agrarian or urban/industrial; fast-paced and lavish or impoverished and hopeless; information-charged or marginally versed; technology-advanced or applications-underdeveloped.

According to the 1990 US Census, New York has 17.9 million residents, making it the second-most populated state in the nation. Approximately 2.5 million New Yorkers - a number greater than or equal to the entire populations of 20 states - are known to have a disability. Preliminary results of a survey conducted for the TRAIID Project indicates that greater availability and access to assistive technology would significantly enable a large majority of persons with disabilities to exercise greater control over life and to benefit from New York's diverse and unique opportunities.

Making inroads into the technology-related assistance needs of New Yorkers with disabilities requires an understanding of the state's demographics. New York City, the most populous city in the nation, has a rich industrial and manufacturing history that has made it a mecca for people in search of a better life. However, the problems of urban life, which place individuals at-risk to be born with or incur a disability, are also magnified within the city's densely populated confines.

Among the city's 7.5 million residents are over 2.2 million persons of Hispanic origin; over 2.8 million African-Americans; almost 700,000 Asians and Pacific Islanders; and over 60,000 American Indians. Translation services are provided in 19 different languages to people for whom English is a second, usually not-yet-acquired, language. Language and cultural differences often pose barriers to both delivering, in a culturally competent manner, and obtaining appropriate assistive technology and services.

New York's upstate rural aspects counterpoint its downstate urban aspects. Despite popular misperception, agriculture is the number one industry in the state. Persons with disabilities residing in rural counties face different barriers to accessing assistive technology, including: inadequate information about service availability, non-existent local service providers and the lack of accessible transportation to travel to services in another nearby county.

There are also international dimensions to the service needs of underserved and unserved communities. For example, the territory of the Akwasansne Mohawk Nation spans portions of Franklin County, New York and parts of Canada. There is no reliable data base on the nature and scope of disabilities of Nation members, although estimates fall in the range of 30 to 40 percent. The situation is compounded by inordinate levels of poverty, as well as social and geographic isolation.

Based upon our knowledge of both programmatic disability issues and trends and this state's socio-political-economic realities, OAD staff has always been convinced that the needs of individuals with disabilities can best be met through services and programs provided by generic service delivery agencies. To that end, agency staff works with at least 50 of the more than 70 executive agencies of state government, as well as with statewide service providers, labor unions and business and industry, to create awareness and identify cost-effective strategies to serve those with disabilities.

TRAIID's primary goal is to make a major contribution to the much needed reform in the way goods, services and supports are provided to New Yorkers with disabilities. To achieve this goal, a comprehensive, customer-responsive outreach and implementation system was developed that advances human potential through access to and use of assistive technology.

In attempting to effect systems change, the TRAIID Project has chosen to implement a two-prong approach generating input and initiatives from both the top-down and the bottom-up. Project staff at the central office level maintain responsibility for systems change through administrative state agency policy, procedures and program operations related activities. Outreach at the local community level is achieved through Regional TRAIID Centers which promote grassroots involvement of consumers, nurturing their awareness of the potential role of assistive technology, and expanding the options for available access to desired services and devices. The intent of these activities is to increase both knowledge and empowerment, since an informed consumer can better self advocate to bring about desired change.

Being situated in a systems advocacy agency has afforded New York's TRAIID Project a unique opportunity to understand the strategies necessary for collaboration and the practical realities of the time involved in convening key players, raising awareness, and negotiating arrangements yielding systems change. Absent responsibilities for direct service delivery and control of service dollars historically has

provided OAD more freedom in its approach to recommending policy revisions. People are most willing to consider change when they do not perceive any threat to themselves or their agency's prerogatives. The TRAIID Project has been able to greatly benefit from this philosophy in its efforts to facilitate change in service systems. Placement in an agency which might have a dual role in both direct service delivery and attempts to effect systems change may have impaired the progress in New York State.

The TRAIID Project thusfar has established five regional technology centers (RTCs). This year will see the development of another center in the North Country of our state. Even with six centers funded, many residents of the state still have to travel long distances to reach the center nearest to where they reside. These centers often serve as the first point-of-contact for people interested in accessing assistive technology on a local level. Centers offer device demonstrations, information and referral to local resources, community outreach, coordination of device assessment and selection, education, training and advocacy services.

During the last nine months, the RTC's provided 1253 product demonstrations to 448 persons with disabilities, 382 family members, 376 providers, and 47 employers. Since receipt of the initial grant in 1990, OAD instituted procedures to expand access to "AT" information and track information requests. Since October, 1992, a six month period, OAD has received 8432 information and referral (I&R) calls. Of that total, 1,220, or 14 1/2 percent, have been "AT" related calls.

TRAID-IN, an Equipment Exchange Service instituted in October, 1992, has generated phenomenal interest. After an initial public awareness effort through a Governor's Press Release, consumer participation increased 600%. Arrangements with a public utility company for an information insert in their monthly bill resulted in further expansion of interest. In the month of October, 1992, we received 10 TRAIID-IN calls. In comparison, in April, 1993, we are averaging 10-12 calls per day.

The State has made significant progress in developing and implementing a statewide program of Technology-Related Assistance under its Title I Development Grant. It had become evident that several initiatives by various New York State Agencies focus on some aspect of assistive technology. Although a number of state agencies are represented on the TRAIID Advisory Board, it became obvious that a vehicle to bring together the key players in those activities was crucial. The TRAIID Project wanted to ensure an opportunity to articulate a common vision for future access that endorsed consumer involvement as equal partners, supported the state's economic and human resource commitments and promoted prudent planning of use of limited fiscal resources.

A meeting of Commissioners, or their designees, from the key state agencies involved in the myriad aspects of assistive technology delivery was convened. The outcome was the recognition of the need for collaboration in the development of policy and planning for future access; the commitment to form an Interagency

Partnership; and the drafting of a Mission Statement to guide their ongoing activities.

MISSION STATEMENT

To assure access to an individual and family centered network of high quality assistive technology and related services that is flexible, responsive, and cost effective.

Arrangements were made to reconvene meetings in February, 1993. Consumers, including family members, and providers, meeting in separate sessions, identified pros and cons of the project's activities on a state and local level and developed recommendations for consideration in designing Year Four TRAIID activities. The areas discussed were organized under Information and Referral, Direct Services and Training. The Interagency Partnership was also reconvened to address the broader issue of imbuing consumer responsive approaches in the strategic planning of a comprehensive assistive technology service system with a life beyond the Tech Act grant period. The participants identified concepts from which goals could be developed which would be the catalyst to sustain or initiate activities that would fulfill their mission and result in systems change.

The Partnership will provide the forum for discussing many of the issues involved in negotiating policy and program revisions necessary to implement a consumer-driven statewide system.

There are potential impacts across all age ranges. Affordable access to assistive technology may be a complement or a partial replacement for the currently used, more labor-intensive strategies, provided an appropriate array of individual and family support services are simultaneously available. Coordination with the IDEA and Rehab Act are crucial to systems change. Part H of IDEA will allow access to infants and toddlers through a family focused process of choice and acquisition. Chapter 428 of the 1992 Laws of the State of New York implements Part H under the NYS Department of Health. The TRAIID project recommendation for inclusion of assistive technology services and devices were reflected in the statutes definition section. TRAIID participated in a Task Group exploring a financing methodology which will include AT in the Early Intervention program. In addition, a competitive RFP for demonstration projects solicits proposals that promote AT as an early intervention

service. Applications require collaboration with RTCs and local AT providers in their design and implementation. Long term effects on systems change will result from families experiencing the benefits of assistive tech as an early intervention service and the impact on their perceptions of their child, the provider community and the desired features of delivery systems.

Assistive technology as a supplementary and or related service in approved IEP's opens the options for choosing lesser restrictive education environments. Transition planning, which links exiting students to career/skills training and community services is of utmost importance, and technology can play a significant role at this time. Project staff are members of the Technology Committee of the State Education Department Regents Select Committee on Disability. The committee developed recommendations to eliminate barriers and improve access to AT devices and services to be considered for inclusion in the final report to the Board of Regents. The lack of publication of the state promulgated IDEA regulations has been problematic. While New York State has indicated efforts to draft state guidelines in concert with the consumer responsive focus of the Tech Act, there has been a limited ability to leverage any shift in existing funding to cover the broader parameters governing when assistive technology should be considered and how services and devices are delivered.

Similar drawbacks exist, as states await final federal regulations for the reauthorization of the Rehabilitation Act. The Act itself clearly promotes consideration of the role of assistive technology at all stages of the rehab process. The combination of recent legislation such as the Americans with Disabilities Act (P.L. 101-336) with creative incentives such as supported employment (e.g., job coaches), and advances in assistive technology, appear to be breaking down many of the barriers to employment opportunities.

Historically, there has been great strength in the definitions of assistive technology devices and assistive technology services incorporated verbatim into other significant disability-related statutes (IDEA, DD Act, Rehab. Act). In order to continue this strategy to have disability statutes reflect a consistent philosophy, we recommend incorporating the specific language from both ADA and the policy statements on the Rehab Amendments. Previous efforts by Congress to solicit consumer participation and commit their suggestions to actual statutory language should not need to be second-guessed and revisited, but rather further empowered in this Tech Act reauthorization legislation. We encourage you to embrace a consumer Bill of Rights that reflects the values and philosophy of consumer responsiveness and the principles of presumed ability, choice and full integration and participation as set forth in the reauthorization of the Rehabilitation Act and the Americans with Disabilities Act.

Most informal care for elderly adults is provided at home. Products for individuals in this older age group need to be particularly user-friendly and accessible. Many elderly individuals lack exposure to or knowledge of assistive devices, and are frightened or put off by the term "technology."

The Center for Therapeutic Applications of Technology in Buffalo, New York, which is also a TRAIID Project Regional Technology Center, is a NIDRR funded Rehab Engineering Center on assistive technology for older persons with disabilities. The REC on Aging has three research programs which represent the main elements of assistive technology utilization: consumer assessments, environmental design and public awareness and access. The reauthorization of the Older Americans Act in October, 1992 mandates a White House Conference on Aging to be held in December, 1994. Recognizing that this population is one of the fastest growing demographic groups, efforts should be made in reauthorizing the Tech Act to ensure it complements the potential positive impact of the implementation of both the Older Americans Act and the White House conference.

Persons skeptical or reluctant to effect changes can validly state that the Tech Act is currently time-limited. Efforts to use the Tech Act philosophy of consumer responsiveness to influence the number and scope of services under related disability statutes needs the credibility that this law is a keystone seen worthy of reauthorization and eventual permanent status. A strong argument for continuation of the state grants is the preservation of the initiatives to set the stage for implementation of 21st century strategies regardless of existing vested interests.

Most of the funding of AT devices and services has been force fit into existing eligibility criteria, service definitions, and device categories used by public and private insurance sources. These often prove inadequate. For example, as individual states struggle with systems change, there is variability amongst federal HCFA regional office interpretations of what can be covered under Medicare and Medicaid. The TRAIID Project continues to work in an inter-agency capacity, to advocate for the inclusion of technology-related planning and funding options. New York's Alternative and Augmentative Communication (AAC) Medicaid Guidelines have become a national model. In 1993, the TRAIID Project sponsored training on the guidelines to over 200 professionals, consumers and advocates. Efforts will continue through our collaborative relationship with the NYS Department of Health to assist them in their evaluation of the impact and effectiveness to both the consumer recipients of the devices and the cost efficiency to the system. TRAIID has initiated dialogue with Medicaid decision makers concerning seating, positioning and wheeled mobility with a focus on the role of assessments in matching individual characteristics with product features to identify cost efficient selections for funding approvals. We will continue to explore on an interagency level the development of Medicaid policy and funding guidelines for seating and positioning, based on the principles of functional necessity and protocols comparable to those designed for the provision of AAC.

Persons are also seeking methods to supplement or use as an alternative to public funding streams. The ability to design programs that create credit ratings and leverage opportunities for consumers to apply, and lenders to make available, lending vehicles to assistive technology promotes independence and fuller participation in the consumer marketplace. It seems premature to mandate loan programs but more important to authorize their development as a financing option.

Although Title I Development Projects focus primarily on systems change, the need to support individual case advocacy for consumers and their family members to obtain assistive technology devices and services must be recognized. The provision of support for advocacy services is consistent with the statement of policy in the 1992 Rehab Act amendment. It's particularly prudent to endeavor to secure supplemental funding to cover these important consumer advocacy services. Any statutory emphasis to funding advocacy services in the reauthorization should ensure that the arrangements implemented would be under the control of the state Tech Act grantee and foster flexibility to reflect collaborative initiatives that could work best in each state. Such flexibility will not endanger advocacy efforts and initiatives that have proven to be effective and consumer-responsive.

Since its inception, the New York Project has placed a great deal of emphasis on capacity building by promoting systems change. Although New York is a state perceived to be rich in resources, the severe fiscal crisis experienced in the last few years has made it a challenge to access the limited resources actually available. The definition of "service" under the Act includes a broad array of interventions necessary for successful selection, acquisition and ongoing use. Information broker, demonstrations, coordinator and technology consultant for assessments, training and trouble shooting and repairs are as vital as the AT devices themselves. The implementation of the TRAIID Project has enabled New York's citizens to become more aware of the potential of "AT." The desired outcome for an increased consumer demand has conversely amplified the impact of our tight fiscal climate.

New York realizes that increased Title I funding should not be perceived as the panacea, however, the per capita award for all of New York State was markedly less than received by other states. The grant awarded to a neighboring state amounted to \$1.00 per resident, whereas New York's second year grant was the equivalent of \$.03 per capita.

The demand on Title I states to not only affect systems change but also provide a range of direct AT related service has posed a significant strain on the ability to accommodate the differential volume of requests based on individual state characteristics.

For example, one of the Title I states, receiving a larger grant award than the State of New York, responded to slightly over 1,000 AT related information and referral calls in a 12 month period, whereas New York has responded to almost 2 1/2 times that amount in a comparable period.

An equipment exchange program operated by another Title I recipient yields an average of 39 calls per month. This program has been operating for a period of five years and provides a service to multiple states. In contrast, operating since October, 1992, the TRAIID-IN Service, serving New York alone has over 300 items currently listed on its' exchange database and receives an average of 10 to 12 calls per day directly related to increased awareness activities.

The TRAIID Project and the agencies represented on the Governor's Human Services Subcabinet are committed to building on existing inroads for changes effecting all New Yorkers with disabilities. As decisions are made concerning the criteria for future funding allocations and continuation decisions, we request consideration of a more equitable approach to determine grant awards. Factors that relate to the demographic diversity such as state's geography, population size, multi-lingual and cultural sensitivity and realistic costs of effecting the scope of changes to impact expanded consumer options in a state should drive award decisions.

Thank you for the opportunity to speak with you today.

Chairman OWENS. Thank you.

Ms. M. Nell Bailey, the RESNA Technical Assistance Project.

Ms. BAILEY. Good morning. My name is Nell Bailey. I am manager of the RESNA Technical Assistance Project. I was asked to provide comments on the reauthorization of the Technology-Related Assistance Act of 1988 from my perspective as manager of the Technical Assistance Project.

Specifically, I will be talking about the progress States are making in achieving the overall goal of establishing a consumer-responsive comprehensive system of technology-related services.

RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technologies, has been under contract to the National Institute on Disability and Rehabilitation Research since 1989 to provide technical assistance and information to States and organizations as they develop and implement technology-related assistance programs under the Assistive Technology Act.

The Assistive Technology Act as passed in 1988 included two features unique in Federal legislation: comprehensiveness, meaning serving individuals with disabilities of all ages across the entire State, and the term "consumer responsive."

The Act was intended to serve as a catalyst for systems change to make assistive technology devices and services readily available as tools for living, learning, working and playing, and to enhance the independence, productivity, integration and quality of life.

States have integrated these unique features into the implementation of their projects, and are continuing to define, refine, and address them.

It has been very exciting for us on the RESNA Project to see the new working relationships being developed. State agency personnel, consumers, professionals, researchers, manufacturers, and public and private third-party payers are coming together to forge a new standard of service delivery which is more responsive to the needs of the consumer.

In addition, States have made progress in such areas as funding and public policy, consumer involvement, interagency coordination, service delivery, and systems change.

Let me just take a few minutes to highlight some of the activities of the States in these areas.

Under the area of funding and public policy, State projects have become knowledgeable about Federal and State laws which fund the delivery of assistive technology devices and services.

Many States became aware early on that this was a full-time activity and therefore included a position on their project for an individual to devote their time solely to this area.

Many States have conducted funding studies which identified the barriers to funding technology-related services. Other studies have examined financial capacity of families which include disability and also are documenting the costs/benefits of providing assistive technology for use at home, at school, work and in recreation.

Several States have compiled guides to funding assistive technology specific to their States. Many States have expanded the availability of funding under programs such as medicaid, special education, and vocational rehabilitation through education and training

on current public policies, through interagency coordination, and in a few instances through appeals and fair hearings.

Under interagency coordination, because the Assistive Technology Act is comprehensive, including all ages and all disabilities, State projects are working with the spectrum of public and private agencies who do or should be providing technology-related assistance.

These agencies almost always are represented on State advisory councils, or in the case of some projects, the agencies are represented on interagency councils whose members are sometimes appointed by the governor.

The legislature here in the Commonwealth of Virginia, in February of this year, as Ken mentioned, passed a resolution which directs all public and State agencies servicing individuals with disabilities to develop and implement policies and procedures specific to the provision of assistive technology services, information, and devices. The overall purpose is to assist consumers in receiving appropriate coordinated services.

As States continue to identify barriers and gaps in their systems, these linkages are critical to implementing strategies for change.

The Assistive Technology Act facilitates access to assistive technology by providing the mechanisms through which States can make systems change in the delivery of technology-related services.

I think it is important to remember that systems change is a process and that it takes time. That is why it is important to continue the activities that the States have started by funding the Assistive Technology Act program for at least another 3 years.

Systems change represents a change in policy and practice and affects many individuals rather than just one person.

Systems advocacy can produce this change, as we have seen in one particular case in the State of Indiana, where the parents of a young man with a disability worked with the special education department in their State to get assistive technology services for their son.

In setting out to get access to assistive technology services for their son, a much larger change occurred. The State adopted a statewide policy which affirmed that the school corporations within the State of Indiana have a responsibility to provide assistive technology and augmentative communication evaluations.

Under the area of consumer involvement, individuals with disabilities are heavily involved in most State projects, usually as members of advisory bodies, where they represent a majority of the membership.

In addition, many States are involving consumers in training their peers on the existence and benefits of assistive technology, on where to obtain services and how to access funding resources.

Training for professionals usually has included sessions on meaningful involvement of consumers in the selection of appropriate equipment.

Although some States are having difficulty in compensating and reimbursing consumers for their time and expenses, many States do.

States are encouraged to include consumers in the decisionmaking process when it comes to the implementation of the project, rather than just in an advisory capacity.

Many States have been pleasantly surprised that, through involving consumers on their projects, they have groomed leaders who are taking positions on other disability boards and on the advisory boards of other agencies and organizations.

The State of Missouri just recently introduced legislation—it was passed by the House and is due to be passed by the Senate this week—which crafts into law an Advisory Council on Assistive Technology and its role in policy analysis and advocacy.

Few States under Title I grants have adequate resources to meet the needs for providing direct services other than information, referral, and demonstration and equipment loan.

However, many States are being creative when it comes to the delivery of technology-related services, especially in addressing the issue of statewideness.

Mobile van units are providing equipment demonstration, fabrication, maintenance and repair of equipment, and in some instances, assessments, evaluations are included as part of the mobile service.

Some States are funding individual assessments where no other resource currently exists.

All States have established information and referral systems. Most of these systems provide information on devices, services, and resources.

The State of New Mexico has a menu-driven user-friendly system which provides information on funding and how to appeal decisions made by various funding sources.

The State of Nebraska has networked information systems in the field through their peer support groups with their central information system.

Even with the progress that the States have made over the past 3½ years, there still are too many individuals who are not able to access affordable technology due to systemic barriers which stand in the way. Areas that continue to need attention are funding, training, and advocacy.

Efforts toward funding and linkages with State agencies and organizations should continue. Training activities should now concentrate on skills and competency, rather than awareness level training, and more emphasis should be placed on systems change in the statute.

One area that is of great concern to me, and one in which I have been asked to comment about today, is the area of outreach, specifically to culturally-diverse populations.

There has been much activity centered around public awareness in a one-time effort which is made to inform individuals in disabilities, their family representatives or service providers about the benefits and uses of assistive technology.

The next step to be taken is for States to develop an outreach plan which targets specifically those populations which have not been served.

Populations which should be targeted are culturally-diverse populations such as African-Americans, Hispanic, Native Americans,

and Asians; individuals with hearing impairments; individuals with multiple disabilities; older Americans; the economically disadvantaged, as well as individuals with disabilities living in rural areas.

The outreach plan should include identification and needs assessments—which groups are you targeting and what are the needs—accessibility of service provision—making the services available in terms of distance—and cultural competency—making sure that the individuals who are providing the services are sensitive to the needs and differences of the various underserved and unserved groups.

A more aggressive campaign should be undertaken to recruit and hire qualified staff from culturally-diverse groups to fill positions on State projects.

Under Title II, especially the training initiative, there should be some assurance that includes linkages with Historically Black Colleges, especially those that provide a program in special education and rehabilitation.

There has been significant progress and learning by States and others during the first 3½ years of implementation of the Assistive Technology Act.

As momentum builds in the 42 States already funded, it has become clear that it will take more than 5 years to achieve the purposes of this legislation.

It has also become clear that the major barriers to individuals accessing assistive technology devices and services are embedded in outdated or poorly-implemented public policies and the resulting inadequate allocation of resources.

The Assistive Technology Act has been the catalyst to mobile joint efforts among consumer service providers and State agencies.

I have just given a very surface overview of some of the progress States are making towards providing access to technology-related services. We need to press on and finish the job that has been started.

Thank you.

[The prepared statement of M. Nell Bailey follows.]

STATEMENT OF M. NELL BAILEY, PROJECT MANAGER, RESNA TECHNICAL ASSISTANCE PROJECT

Good morning! My name is Nell Bailey. I am Project Manager of the RESNA Technical Assistance Project. I was asked to provide comments on the reauthorization of the *Technology-Related Assistance for Individuals with Disabilities Act of 1988 [P.L. 100-407]* from my perspective as manager of the Technical Assistance Project. Specifically, I will be talking about progress States are making in achieving the overall goal of establishing a "comprehensive, consumer-responsive system of technology-related services." I will also be talking about outreach to underserved and unserved populations.

RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technologies, has been under contract to the National Institute on Disability and Rehabilitation Research since 1989 to provide technical assistance and information to States and organizations as they develop and implement technology-related assistance programs under P.L. 100-407.

Since the passage of the Assistive Technology Act, there have been other factors which have increased the demands placed on States by the Act. Increased emphasis on the delivery of assistive technology by other Federal legislation and reduced State budgets in medicaid, special education, and vocational rehabilitation have created unique opportunities and challenges for State agencies, consumers, and professionals. At the same time, more and more individuals with disabilities and their families, administrators, and professionals are beginning to learn about the power-

ful role assistive technology can play in increasing the independence and productivity of individuals with disabilities. With these two forces coming together—less funding and a demand for more services—pressure is mounting to find creative funding solutions to pay for assistive technology services through the Assistive Technology Act. The RESNA Technical Assistance Project is helping States to meet these challenges by providing nationwide technical assistance. This technical assistance includes the provision of training opportunities, information products, and individualized consultation specific to States' needs.

The Assistive Technology Act as passed in 1988 included two features unique in Federal legislation: comprehensiveness—i.e., serving individuals with disabilities of all ages across the entire State—and, introduction of the term “consumer responsive.” The Act was intended also to serve as a catalyst for systems change to make assistive technology devices and services readily available as tools for living, learning, working and playing, and to enhance independence, productivity, integration and quality of life. States have taken these unique features into consideration in the implementation of their projects and are continuing to define, refine, and address them.

From a TA Project perspective, States have made significant progress in meeting the purposes of the Act as outlined in section 2(b)1 of the statute. The evaluation report by Research Triangle Institute also documents that substantial progress has been made on the part of the State Assistive Technology Act projects in meeting the stated purposes of the Act. Consumers, service providers, and State agencies are more aware of assistive technology and have an understanding of the many kinds and various types of devices. Consumers are also able to access information about assistive technology in most States. Barriers to funding of assistive technology devices and services have been identified and States are beginning to explore solutions to these barriers through improving coordination among agencies, consumers and service providers.

It has been very exciting for us on the RESNA Project to see the new working relationships being developed; State agency personnel, consumers, professionals, researchers, manufacturers, and public and private third-party payers are coming together to forge a new standard of service delivery which is more responsive to the needs of the consumer.

In addition, States have made progress in such areas as funding and public policy, consumer involvement, interagency coordination, service delivery, and systems change. Let me just take a few minutes to highlight some of the States activities in these areas.

Funding and Public Policy

State projects have become knowledgeable about Federal and State laws which fund the delivery of assistive technology devices and services. Many States became aware early on that this was a full-time activity and therefore, included a position on their project for an individual to devote their time solely to this area. Many States have conducted funding studies which identified the barriers to funding technology-related services. Other State studies have examined financial capacity of families which include disability and also are documenting the costs/benefits of providing assistive technology for use at home, school, work and in recreation. Several States have compiled “Guides to Assistive Technology Funding” specific to their States.

Many States have expanded the availability of funding under programs such as medicaid, special education and vocational rehabilitation through education and training on current public policies, through interagency coordination, and in a few instances, through appeals and fair hearings.

Interagency Coordination

Because the Assistive Technology Act is comprehensive, including all ages and all disabilities, State projects are working with the spectrum of public and private agencies who do or should be providing technology-related assistance. These agencies almost always are represented on State advisory councils or, in the case of some State projects, the agencies are represented on interagency councils whose members are sometimes appointed by the governor. The legislature here in the Commonwealth of Virginia, in February of this year, passed a resolution which directs all public and State and local agencies servicing individuals with disabilities to develop and implement policies and procedures specific to the provision of assistive technology information, services and devices. The overall purpose is to assist consumers in receiving appropriate, coordinated services. As States continue to identify barriers and gaps in their systems, these linkages are critical to implementing strategies for change.

Systems Change

The Assistive Technology Act facilitates access to assistive technology by providing the mechanisms through which States can make systems change in the delivery of technology-related services. I think it's important to remember that systems change is a process and that it takes time. That is why it's important to continue the activities States have started by funding the Assistive Technology Act program for at least another three years.

Systems change represents a change in policy and practice and affects many individuals rather than just one individual. Systems advocacy can produce this change as we have seen in one particular case where the parents of a young man with a disability worked with the special education department in their State to get assistive technology services for their son. In setting out to get access to assistive technology services for their son, a much larger change occurred: the State adopted a policy affirming that school corporations have a responsibility to provide assistive technology/augmentative communication evaluations. And based on a case-by-case decision of the student's educational needs, if this evaluation determines that assistive technology equipment or services are needed for a student to benefit from a free appropriate public education, the school must provide this service and equipment at no cost to the student.

Consumer Involvement

Individuals with disabilities are heavily involved in most State projects, usually as members of advisory bodies, where they represent a majority of the membership. In addition, many States are involving consumers in training their peers on the existence and benefits of assistive technology, on where to obtain services and how to access funding resources.

Training for professionals usually has included sessions on meaningful involvement of consumers in the selection of appropriate equipment. Although some States are having difficulty in compensating and reimbursing consumers for their time and expenses, many States do. Some State projects provide the financial support for consumers to attend national and State conferences. States are encouraged to include consumers in the decisionmaking process when it comes to the implementation of the project rather than just in an advisory capacity. Many States have been pleasantly surprised that through involving consumers on their projects, they have groomed leaders who are taking positions on other disability agencies' and organizations' boards. The State of Missouri just recently introduced legislation (it was passed by the House and is due to be voted on by the Senate during this week) which crafted into law an advisory council on assistive technology and its role in policy analysis and advocacy. State projects have used consumers to review competitive subgrant proposals and also to head up and work on various task forces looking at specific technology-related issues.

Service Delivery

Few States have found the Title I grants adequate to meet the needs for providing direct services, other than information, referral, and demonstration and equipment loan. However, many States are being creative when it comes to the delivery of technology-related services, especially in addressing the issue of statewide service. Mobile van units are providing equipment demonstration, fabrication, maintenance and repair of equipment. In some instances, assessments are included as part of this mobile service. Some States are funding individual assessments where no other resource currently exists. Other States are establishing a fee for services now available through local centers established or expanded with Assistive Technology Act funds. Some States are exploring the use of grant moneys to insure financial loan programs. The State of Maine uses an interactive television system to assist them in the provision of assistive technology services.

All States have established an information and referral network, some more sophisticated than others. Most of the systems provide information on devices, services, and resources. New Mexico has established a "menu-driven" system which provides information on funding and how to appeal decisions made by various funding sources such as special education, vocational rehabilitation and Medicaid. The State of Nebraska has networked information systems in the field serving their peer support groups with their central information system.

Ongoing Needs

Even with the progress that the States have made over the past 3½ years, there still are too many individuals who are not able to access affordable technology due to systemic barriers which stand in the way. Areas that continue to need attention are funding, training, and advocacy.

Efforts toward funding and linkages with State agencies and organizations should continue. Training activities should now concentrate on skills and competency rather than awareness level training and more emphasis should be placed on systems advocacy in the statute. By mandating advocacy activities, staff of State projects will be less subjected to the threat of losing their jobs.

Outreach

One area that is very near and dear to me and one in which I have been asked to comment specifically about is the area of outreach—specifically to culturally-diverse populations, and African-Americans in particular. There has been much activity centered around public awareness in which a “one-time” effort is made to inform individuals in disabilities, their family representatives, or service providers about the benefits and uses of assistive technology. The next step to be taken is for States to develop an outreach plan which targets those populations which have not been served or which are underserved. Populations which should be targeted are: culturally-diverse groups (i.e., African-Americans, Hispanics, Native Americans, and Asians); individuals with hearing impairments, individuals with multiple disabilities, older Americans, as well as individuals with disabilities living in rural areas.

The outreach plan should include identification and needs assessments (i.e., which groups are you targeting and what are the needs), accessibility of service provision (i.e., distance to services—rural, urban), and cultural competency (i.e., making sure that the individuals who are providing the services are sensitive to the needs and differences of the various underserved and unserved groups). A more aggressive campaign should be undertaken to recruit and hire qualified staff from culturally-diverse groups to fill positions on State projects.

Under Title II, especially the training initiative, there should be some assurance that includes linkages with historically black colleges especially those that provide a program in special education and/or rehabilitation. An example of such linkage is the Meharry Medical School in Tennessee through the Tennessee Assistive Technology Project, which is planning to have a three-hour training session targeted specifically to African-Americans on the uses and benefits of assistive technology. I would like to see more of these partnerships formed.

Conclusion

There has been significant progress and learning by States and others during the first 3½ years of implementation of the Assistive Technology Act. As momentum builds in the 42 States already funded, it has become clear that it will take more than 5 years to achieve the purposes of this legislation. It has also become clear that the major barriers to individuals accessing assistive technology devices and services are embedded in outdated or poorly-implemented public policies and the resulting inadequate allocation of resources. The Assistive Technology Act has been the catalyst to mobilize joint efforts among consumers, service providers, and State agencies. I have just given a very surface overview of some of the progress States are making towards providing access to technology-related services. We need to press on and finish the job that has been started.

Thank you.

Chairman OWENS. Thank you. I want to thank all the panelists. I will yield to Mr. Scott for questions.

Mr. SCOTT. Thank you, Mr. Chairman.

Ms. Buck, you mentioned funding advocacy. How could we best fund advocacy? There are a number of different formats right now, from parent/lay-advocates to legal aid. How do you think it could best be done, or do we need an array of different services?

Ms. BUCK. In the State of New York, our philosophy about advocacy is that it encompasses four approaches.

There is individual case advocacy, legal advocacy, systems advocacy, and the ultimate is self-advocacy. Based on those principles, I really believe that we need an array of services, because there are a number of resources that currently exist. We also need to recognize that people feel comfortable going to different places. Not everyone feels—one place is not going to be the panacea.

We need to be able to complement the individual's specific needs and also be able to offer a variety of services; promoting the self-

advocacy but also having the provisions to support case advocacy and ultimately legal advocacy as a last resort, if that is ultimately what is needed.

Mr. SCOTT. Do you have any idea what the expense would be for the various forms?

Ms. BUCK. As a comparison, in New York State, the current protection and advocacy program for persons with developmental disabilities receives over \$1 million, and that is only one component directed towards persons with developmental disabilities.

New York State also has 35 independent living centers. There is also protection and advocacy for persons who are diagnosed with mental illness. There are parent training networks.

I think it would be unjust for me to try to guess at an estimate. That would take further research to adequately address the issue.

Mr. SCOTT. You just mentioned developmental disabilities. In your comments, you ran through something about Part H, which I did not completely comprehend.

Ms. BUCK. Part H in New York State is administered by the New York State Department of Health. We have been working very closely with them.

In fact, under Part H the States are required to institute a central directory so that local case managers can help parents identify local services.

In New York State, the Office of Advocate for the Disabled, our information and referral component, also functions as the Part H central directory.

We have been working very closely with the Department of Health staff in ensuring that, in State regulations, the definition of assistive technology devices and services have been included in that.

We have also been working with them to help devise a reimbursement methodology for the purchase of assistive technology. They recently issued an RFP to pilot a number of projects, and we were able to work with them to ensure that in issuing one of those RFPs, assistive technology was one of the targeted areas. It required a collaborative approach, either working with one of the technology centers established under the TRAIID Project or other technology providers throughout the State.

So, we are trying to approach this hand-in-hand to address the issues.

Mr. SCOTT. Under medicaid—how do you decide what to fund under medicaid?

Ms. BUCK. Each State has the flexibility to determine a State medicaid plan. New York State, in fact, is much more open than many States in the Nation.

One of the other things about New York State is I believe it is the only State in the Nation that requires a local share at this point in time. Our locals are pretty much astounded by that, as well.

They developed their plan, and essentially what is not covered under medicaid in most cases for individuals with children can be obtained through the EPSDT, Early Periodic Screening and Diagnostic Testing program.

Mr. SCOTT. You can fund devices under EPSDT?

Ms. BUCK. Yes.

Mr. SCOTT. Ken, did you want to comment?

Mr. KNORR. I did want to make one comment on protection and advocacy.

When we had the All-States Directors Meeting just recently in Boston, that was one of the areas that received a lot of attention from the State directors. I believe I am representing the consensus of the group when I say that the State directors pretty much were in agreement that advocacy is absolutely essential and should be required. But they felt that the way to carry that out should be left exclusively to the individual respective States.

Mr. SCOTT. Ken, you mentioned the Lieutenant Governor's commission. Can you give us some background on some of the recommendations, particularly in systems changes?

Mr. KNORR. Yes, I can, Mr. Scott.

The Beyer Commission had a separate chapter on assistive technology, and within that they made several recommendations that were directly related to assistive technology.

One of them was that some sort of a loan fund be established for long-term change, recognizing that this was one of the most significant needs.

Another one was that several of the State agencies form cooperative agreements. Of course, we took that well beyond that and pulled the 11 State agencies together and formed a single policy for the State of Virginia.

The third specific recommendation that was related to assistive technology was that we set up or establish the regional centers around the State and that they be continued beyond the Federal funding cycle.

Let me say that, in the RFP—that was the process we used, the request for proposal—we actually built in that the individual resource centers or consortia should look towards their own continuance beyond the Federal cycle from the very beginning. We are moving in that direction at this point, trying to make those plans.

Those were the three recommendations that came out of the Beyer Commission. It set the entire stage in Virginia. It was a wonderful boost.

Mr. SCOTT. Just one question for Ms. Bailey, Mr. Chairman.

You had mentioned using Historically Black Colleges and Universities in addressing the needs for the minority community. Could you expand on that?

Ms. BAILEY. Well, particularly the need for training around the benefits and uses of assistive technology.

Right now, in the State of Tennessee, the Meharry Medical School is participating with the Tennessee Assistive Technology Project in hosting a 3-hour training curriculum targeted specifically for African-Americans. That is very exciting, and I think more States need to follow that model.

Mr. SCOTT. Thank you, Mr. Chairman.

Chairman OWENS. In terms of advocacy, Mr. Knorr you said there was agreement among the directors that there should be a requirement to do advocacy?

Mr. KNORR. They all thought that it should be an essential component of—

Chairman OWENS. An essential component. Advocacy should be an essential component.

Mr. KNORR. Yes, it should.

Chairman OWENS. It should be left to the States, you said, as to how they do that.

Mr. KNORR. Yes. As I recall, what the States were looking for was to have certain standards established in terms of what advocacy should look like and then to leave it up to the individual States to be responsive to those standards and to be held fully accountable for them; that the actual implementation would be more effective if done at an individual level by the individual States.

Deborah?

Ms. BUCK. That pretty much reflects our approach to this, as well.

In New York State, we have a very good working relationship with the protection and advocacy agency, the Independent Living Centers. We really respect the latitude that is needed by my colleagues in other States, recognizing that many of them could devise very creative means to address the need for advocacy. That needs to be supported rather than trying to direct activities to one known entity.

Chairman OWENS. So, we are not prohibiting or preventing any States from having advocacy programs now.

Ms. BUCK. No, you are not.

Ms. BAILEY. I think the issue, though, is that when States have tried to do advocacy activities, there have been threats to directors of State programs of losing their jobs. It depends on the agency in which they have been housed.

It is very difficult to try to effect change when you are a program housed in the vocational rehabilitation department and that is the agency you are trying to change.

So, in terms of States providing advocacy services, there have been, in several instances, directors of the projects who have lost their jobs.

Chairman OWENS. Well, that is most unfortunate. I would like to know more about that. Is that a problem in terms of minority outreach, also—

Ms. BAILEY. I do not think so.

Chairman OWENS. [continuing] that there is a danger of them losing their jobs? Why aren't they doing more minority outreach then?

Ms. BAILEY. I cannot speak specifically for the States, but I think, because of the scope of the project, that States have just been concerned with trying to develop a consumer-responsive statewide system. They have gotten the consumer involvement piece but have not gotten to the statewide piece. I guess some States are doing a very good job in the area of outreach, but then there are some States that have not addressed the issue at all.

Chairman OWENS. Other than Virginia, what States are doing an outstanding job, in your opinion?

Ms. BAILEY. Well, I think that, when it comes to Native Americans, New Mexico, Alaska, and Utah are doing good jobs; when it comes to African-Americans, New York, Virginia, Tennessee, and South Carolina.

Chairman OWENS. You said something about a one-time effort. Can you explain what you meant?

Ms. BAILEY. Public awareness activities are directed at getting a message across via a sort of one-shot approach. My definition of this sort of outreach effort is taking a rifle and spraying a larger area and targeting specific groups.

Outreach is just a general approach to trying to reach a large number of people. It is cost-effective, but then when you see that there are groups that are not being served, then I think you need to specifically target those groups.

Chairman OWENS. How long has your agency been funded for this contract?

Ms. BAILEY. We had a 3-year contract. The first contract was awarded in 1989, and we just got a new 2-year contract October 1 of 1992.

Chairman OWENS. What is the amount of the contract?

Ms. BAILEY. The original amount was \$500,000 a year, and our new contract, which includes an additional task of information dissemination, is for \$600,000.

Chairman OWENS. How many staff members do you have?

Ms. BAILEY. Five full-time staff members. We work with a network of consultants, three specifically, but then we have other consultants as part of our larger network.

Chairman OWENS. What do you think of the recommendation that a national information network be established? How does that overlap with what you are doing?

Ms. BAILEY. I think there probably is some overlap, but I am not sure what a national information network would include.

If its purpose is to provide a clearinghouse for information, I am not sure if it is needed. I think that all of the States have established information and referral systems. There should be some kind of support available for those States to maintain, build upon, and expand the I&R systems they have already in place.

Chairman OWENS. Would either of you like to comment on that?

Ms. BUCK. I would like to. Speaking from a State that has maintained an information and referral service for about 10 years, I prefer to maintain that on a State level.

We currently have over 600,000 items on information and referral in our computerized database, and the effort to maintain the accuracy and consistency of that information is tremendous. I would be extremely hesitant to support a national I&R system. I would be very cautious about the quality of information involved in that.

What I would support, however, is a national I&R access in terms of specific devices in the form of ABLEDATA. ABLEDATA, which individuals can access through our bulletin board service from their home, currently has 17,000 to 20,000 items of devices listed on it. Even that needs to be maintained.

Obviously, technology changes daily, and I am sure the effort to ensure that it is reflective of changing technologies is vital, but it is also a very large job.

Chairman OWENS. Is the information and referral service in New York State just for assistive technology?

Ms. BUCK. No, it is not. As I said, it has been operating for 10 years, and only until we got the assistive technology grant did we then add in that component.

We were doing referrals for assistive technology if someone would call up and look for wheelchairs, but we did not have the methodology on our computerized database at that point specifically identified as AT and we were not tracking it. We have since made those changes.

Our information and referral database is a single entry point for persons for the State. It responds to any question related to a disability issue from birth to death, and people can get it in a multitude of formats. Adding the assistive technology and the Part H central directory ensures that it is a more comprehensive approach. Generally, when people call up asking for assistive technology, that is not the only thing that they need.

They need the additional services that go with it, the training, et cetera, and a comprehensive database such as ours provides one-stop shopping.

Chairman OWENS. Would it not be improved if you had a national hook-up so that you could tell the Native Americans in New York State what they are doing for Native Americans in New Mexico, since that is a model program out there?

Ms. BUCK. Some of those things can already be accomplished through current networks, such as AppleLink, SpecialNet, Internet, that already exist.

I mean you can sit down and spend all day at your computer networking. RESNA links us with the—I mean they are a vital resource in terms of finding out what other people are doing and being able to disseminate and share that information.

Chairman OWENS. Mr. Knorr.

Mr. KNORR. I fully agree with what Deborah has said. I think it is very important, on a national level, to keep the databases updated on devices. I think that is very relevant for everyone across all of the States.

However, that is not the only information that the consumers are looking for. They are also saying, "Now that you have told me about this device, where can I get training in how to use this device, where can I purchase the device, how can I receive funding support for this device?"

That information has to be locally and regionally developed and specific for their needs. So, I support fully what Deborah said.

Chairman OWENS. It is absolutely essential that every State have an adequate information and referral setup.

Mr. KNORR. I feel it is very important.

Chairman OWENS. You can supplement that by having certain specialized information fed into it from other places.

Mr. KNORR. Yes, sir, exactly.

I would also like to comment on one thing that Nell had mentioned.

In the State of Virginia, we are administered by the Department of Rehabilitative Services, and I would like to say that we have enjoyed a wonderful relationship with them. They have provided incredible support to us in terms of staff resources and technical support.

Although we are housed in the Department of Rehabilitative Services, our Commissioner says that it is a right that each individual have the technology they need and that it is my job to make sure that we advocate for that right.

So, we have received nothing but full support from them. The Commissioner is involved in the actual design of this program and ongoing supervision.

So, I think that speaks to the fact that implementation in each State should be left up to the States. What we need to be told is what is it that we need to accomplish and then be held accountable for it.

If it does not work in one State within a particular system, fix that particular problem, but do not attempt to mandate to the States that it should be housed in a particular type of activity.

Chairman OWENS. Would you say the same thing is true of New York, Ms. Buck—

Ms. BUCK. Yes, I would, exactly.

Chairman OWENS. [continuing] a positive relationship between the program and the State?

Ms. BUCK. Our agency has never had responsibilities to provide direct services until receipt of this grant. We have always been a systems advocacy agency, and that has put us in a very key position in being able to bring about systems change.

We have a very close working relationship with the Commissioner of VR. We are trying to work closely with the State Education Department, particularly with regards to Ms. Somoza, and they are represented on our interagency board on Assistive Technology.

One of the things I would recommend, though, is that, in ensuring that States have flexibility to have the governor determine what agency can most effectively institute the program, I think there needs to be a safeguard for those projects; as Ken said, clearly identify what their responsibilities are but safeguard their ability to actually advocate for the changes that are needed.

Could I go back and identify one other benefit of the State I&R project as opposed to a nationwide one?

Chairman OWENS. Sure.

Ms. BUCK. One of the ways that our State I&R has been of benefit is that it helps us to identify what systems change problems need to be addressed.

For example, we track every call that comes in; the type of call, what county it comes from, the content, and where it is referred.

We can go back to that data and identify where the problem is. Is somebody having a lot of problems with workman's compensation? Is it with medicaid/medicare? Exactly where is the problem?

Is it a statewide policy level issue that needs to be intervened on a commission level, or is it more a matter of dissemination of information—someone in a local county is not getting the appropriate information that the statewide level entity has already agreed to?

So, it very much helps in the systems advocacy responsibility to identify those problems where we, as agency collaborators, can intervene and bring about the changes that are needed.

Chairman OWENS. While you have the mike, Ms. Buck, there are a couple of other questions I would like for you to elaborate on.

Does the State of New York supplement the funding for this program? You mentioned that the population is so much greater than in other States, yet your funding level is about equal to those States. What hardships does that create, or is the State rich enough to provide some of the funding?

Ms. BUCK. I will share with you that, in the last 5 years, because of the State's fiscal crisis, the New York State Office of Advocate for the Disabled has lost more than 50 percent of its staff.

Separate from that issue, they do supplement the project with many in-kind costs. They provide all of our office space, a lot of support services, et cetera.

There are staff that are directed to provide in-kind services to us: our attorney, the fiscal personnel officer, all of the other key community development people.

Everything in our agency is, again, seen as a holistic approach, so that when someone is in the community talking about accessible transportation issues or the ADA, they are also talking about assistive technology.

Chairman OWENS. What is the amount of the funding that you receive in New York State for this project?

Ms. BUCK. We get \$615,000.

Chairman OWENS. Ms. Bailey, how does that compare to most States?

Ms. BAILEY. I think it is a little above what most States are getting. New York is still in its development phase. This is part of their extension grant.

So, most of the States in the development phase are getting an average of \$525,000, I would think.

Chairman OWENS. Most of the States? New Mexico?

Ms. BAILEY. I would think so.

Chairman OWENS. Rhode Island? Delaware? They are all getting about \$500,000?

Ms. BAILEY. The law says a minimum of \$500,000.

Chairman OWENS. I just want certain things on the record here. California and New York get about \$600,000.

Ms. BAILEY. California has not been funded yet.

Chairman OWENS. Oh, California has not been funded yet.

Ms. BAILEY. Right, but Texas does.

Chairman OWENS. Texas gets \$600,000.

Ms. BAILEY. About \$500,000.

Chairman OWENS. Florida, Texas, California, the most populous States receive about the same, maybe \$100,000 more, you say.

Ms. BUCK. In some of the information that is available, from what I have seen, it seems like many of the other States initially got larger awards. They have tried to increase ours significantly, but we are not that much ahead of—maybe \$2,000—most States.

The other issue to consider as well is that New York is a very high cost-of-living State. For example, you could have a conference and bring in a number of consumers in a midwestern State and provide hotel rooms for people at \$35.

Chairman OWENS. Sticking to the fact that you have a population of 17.9 million and 2.5 million disabled, which is greater than the population of some of the States, there seems to be a problem of inequity which I think we have to address.

Hopefully, we can prevail on the Appropriations Committee and the new administration, not to decrease any grants, but to address the problem of the gross inequities with respect to States with large populations to be served.

Ms. Buck, you stated in your written testimony that it would be premature to require States to establish low-interest loan programs. Can you explain why you feel that is the case?

Ms. BUCK. Well, New York State has a low-interest loan program that, again, has existed for about 10 years. It is administered by our New York State Department of Social Services.

It is a small fund that is funded yearly by the State legislature and is depleted very quickly. It also has an extremely high default rate.

Chairman OWENS. What do you mean "depleted very quickly?" It is so much per year?

Ms. BUCK. It is so much per year. With the very high default rate, with people not paying back, it is difficult to get it to be an actual revolving fund. So, the fund is depleted quickly and people often have to wait until new allocations are made.

We are working very closely with our Department of Social Services to identify those factors that are causing the default issue so that we can develop more creative approaches to the issue.

We endorse the issue of low-interest equipment loan funds, but again, that is not the panacea. It is kind of like the issue of advocacy. There is no one approach that is going to be the right approach.

What we support is the initiative to support very creative efforts in developing forms of financing that, again, will empower people with disabilities, enable them to establish credit ratings, and become more independent, as opposed to being totally reliant on a State-operated system continually.

Chairman OWENS. Do you want to comment on that, Mr. Knorr?

Mr. KNORR. Yes, sir.

Part of the national research that we will be doing as it relates to loan financing will be looking for some creative ways to leverage additional resources.

We are going to be looking at ways to buy down interest rates through a particular fund; get them down to a point where a consumer can afford to take up the loan over a long period of time. Another thing that we will be doing is looking for ways to guarantee the loan so that we will be able to use the commercial banks. This will make it more appealing to folks within the banking industries. We will also be looking at the Community Reinvestment Act to see what leverage that might have with the folks in the banking industries.

I think we all need to look for ways to leverage as many resources as we can. There is a huge need all across the country, and it is going to be very difficult. We need to figure out the best model to introduce in a particular State for loan financing; to figure out how are we going to come up with the funds to put in this kitty.

Sure, it is not going to be as much as for a revolving loan fund where you need up front, but you are still going to need some money to guarantee the loans and to buy down the interest rates. I do not know that any of the individual States at this point have money set aside as we move towards that direction.

Chairman OWENS. While you have the mike, Mr. Knorr, I would like to close out with a question that leads us to another dimension.

Virginia is to be congratulated for its Blue Ribbon Commission which existed prior to the bill's funding, and you, as a result, have jump-started and are way ahead of everybody else. You really have a model program, and I congratulate you on that.

Maybe you can investigate possibilities of going to another level. Are most of the assistive technology devices manufactured in the United States, or do they come from Germany or Japan or other industrialized nations? Do you happen to know offhand?

Ms. BUCK. It varies for different types of devices. For example, many of the wheelchair components are manufactured overseas and are then brought in and combined with other American-made products. It really does vary like many of the computers and the small chips, et cetera.

Chairman OWENS. Well, I was proceeding on the assumption that the laws in the United States with respect to people with disabilities are far ahead of most of the industrialized nations. As a result, I think we are doing some things they are not doing. That will be reflected in the fact that we have created a market for these devices.

I wondered to what degree they are being manufactured here. Is this not an area where we might want to make some recommendations to the President and the Department of Commerce, or if not, an opportunity for some States. I just asked my assistant for a list of manufacturers and wholesalers.

There is an area here that might generate an industry in which we could stay ahead of the rest of the industrialized world and also generate a stream of revenue that might be used to accomplish some of the things you were talking about if we can tie it in some way to that process.

Mr. KNORR. I think it would be very easy to find out the number of manufacturers in the United States versus other areas.

If you look across the country at all the information and referral systems that we have and at what they are doing—putting consumers in touch with more information on devices—we are now able to provide consumers with the same kind of information—various types of models, how efficient, dependable, and reliable they are, and the cost figures that we can get from "Consumer Report" when preparing to buy a car.

Think of how that is not only empowering the consumers but effecting the cost of the various devices as consumers have information on why one costs more than another particular type of device.

Ms. BUCK. The need to encourage capacity-building among manufacturers in New York State and the country at large is vital.

For example, the stand-up chair that Anastasia was using, was developed in a very small town close to Albany, New York.

It is one of the most economically destitute counties in the State. The chair was developed at a boat manufacturing firm which has suffered numerous losses because of the luxury tax. An engineer worked very closely with them to retrofit and retrain some of their employees to start manufacturing this type of device.

Our office gets numerous calls from people who are trying to develop equipment and devices. The New York State—under the Department of Economic Development, the Science and Technology Project actually provides funds for supporting the development of devices that will get to market. They do it on a royalty-type basis, and we sit on that board. There is a greater need for it, and we are going to be working with them to do some training for manufacturers and vendors to clarify their idea and actually bring it to fruition.

Chairman OWENS. I think it is an area that needs to also be explored on a national level. We should look for some tradeoff from the industry as a result of stimulating such development.

Thank you again. I am going to yield to Mr. Scott for the last question.

Mr. SCOTT. I just had a couple of real quick questions.

Ms. BUCK, when you put some of these things on the bulletin board, for example, the availability of devices, how long do they stay on the bulletin board?

Ms. BUCK. The HYPER-ABLEDATA database is on the bulletin board currently. We subscribe to ABLEDATA, and as we get the updates, it is just modified on the bulletin board. So, it is a continual access thing.

Mr. SCOTT. How long does it take someone to find out what is there that they have been waiting for?

Ms. BUCK. Oh, the equipment exchange. The equipment exchange program in the State is still so very new—it has only operated for a 6-month period, and we recently had three matches. So, determining how long equipment eventually stays on there is something that we are still working out.

We are using guidance established by our counterparts in other States who have been operating programs for quite some time, but we are going to have to work that out.

Mr. SCOTT. You mentioned a high default rate. Can you give an estimate of what the default rate is on some of these loans?

Ms. BUCK. Twenty-five percent.

Mr. SCOTT. Seventy-five percent get paid back?

Ms. BUCK. Yes. There are a number of factors that are related to that which need to be clarified.

Many of those services are being accessed by elderly persons who are looking for devices that are currently not covered by medicaid or medicare. There is a 10-year repayment loan, and often the person either dies or the device does not work anymore. It is very hard for someone on an extremely limited income to keep paying on something for 10 years that does not work anymore.

Mr. SCOTT. Your experience is that 75 percent of the loans are paid back?

Ms. BUCK. Yes.

Mr. SCOTT. Ms. Bailey, how long are you funded for?

Ms. BAILEY. For 2 years, beginning October 1992. So, we are funded through September 30, 1994.

Mr. SCOTT. Thank you.

Mr. KNORR. One quick comment on the default rate. From our research around the country, a 25-percent default rate is substantially higher than the national average. I believe someone else will

probably address that in more detail in a few minutes. I just wanted to add that to the record. Thank you.

Chairman OWENS. Thank you again.

Our third panel consists of Dr. Marvin Fifield, the Program Director, Utah State Program for Technology-Related Assistance, from Logan, Utah; Mr. Steve Tremblay, Principal Investigator, Alpha One, South Portland, Maine; Mr. Girish Yajnik, University of South Carolina, Columbia, South Carolina; and Mr. Mark Odum, Principal Investigator, National Rehabilitation Information Center, Silver Spring, Maryland.

Mr. Tremblay has a plane to catch, so we are going to ask him to lead off with the testimony. Mr. Tremblay, we will contact you later with any questions that may not have been covered.

STATEMENTS OF MARVIN FIFIELD, PROGRAM DIRECTOR, UTAH STATE PROGRAM FOR TECHNOLOGY-RELATED ASSISTANCE, LOGAN, UTAH; STEVE TREMBLAY, PRINCIPAL INVESTIGATOR, ALPHA ONE, SOUTH PORTLAND, MAINE; GIRISH YAJNIK, UNIVERSITY OF SOUTH CAROLINA, COLUMBIA, SOUTH CAROLINA; AND MARK ODUM, PRINCIPAL INVESTIGATOR, NATIONAL REHABILITATION INFORMATION CENTER, SILVER SPRING, MARYLAND

Mr. TREMBLAY. Good morning. Thank you. I am Steven Tremblay. I am actually the President and founder of Alpha One, a center for independent living, which is based in South Portland, Maine.

I want to say, first of all, I found it a little humcruous earlier when they were mentioning the boat tax. If I remember, Senator George Mitchell, from back home in Maine, a few years ago, was a strong supporter of the boat tax, which ultimately passed. Now he is working vigilantly to repeal that tax so our boatbuilders on the coast of Maine will be able to once again profit, as opposed to make losses.

I want to begin by saying that I am here this morning to tell you about a loan program that we established in the State of Maine in 1988. It was a bold initiative that we undertook in the area of assistive technology.

Following up on the recommendations of the Independent Living Commission, which I chaired, Maine voters were provided the opportunity, through a statewide referendum, to create a \$5 million revolving loan fund for assisting individuals with disabilities, their families, and private businesses in acquiring assistive technology.

The State referendum question asked Maine voters the following: "Do you favor a \$5 million bond issue for the establishment of an adaptive equipment loan fund which would enable persons with disabilities to purchase adaptive equipment necessary to their independence?"

Maine voters responded overwhelmingly in support of this referendum, and it passed with a 60-percent majority.

At the time, with the exception of a few small public agency-based loan programs and one developed by the American Foundation for the Blind, which financed one item of assistive technology

only, experience with this financing strategy was really unavailable.

At the outset, our goal was to establish a loan program with a very specific philosophy. In my opinion, it is this philosophy which has made Maine's program so successful and, I should add, really the envy of the Nation. Let me share with you the guiding principles which govern the program.

1. First and foremost, the program is consumer controlled. This criteria was assured by developing enabling legislation which required a consumer-controlled nine-member oversight Board. The Governor nominates these individuals, who are confirmed by the legislature. The consumers represent cross disabilities.

Furthermore, the enabling legislation strongly recommended that the Board contract with a community-based organization experienced in assisting persons with disabilities to help with administering the program. In Maine's case, Alpha One was hired as the agent.

The legislation also specified that Maine's finance authority would serve as the fiduciary agent for this program. Both of these organizations have proved to be effective and efficient in co-administering this program.

2. The eligibility criteria outlined in the enabling legislation are simple and straightforward. These include the following: (1) a "qualifying borrower" means any individual, profit or non-profit corporation, or partnership which demonstrates that the loan will assist one or more persons with disabilities to improve their independence or become more productive members of the community, and (2) the individual or corporation or partnership must demonstrate creditworthiness and repayment abilities to the satisfaction of the board.

3. The loan program is for people with all types of disabilities. It is also available to private business, which is especially important in light of requirements of the Americans with Disabilities Act.

4. As little as \$250 or as much as \$50,000 may be loaned to a qualified borrower.

5. Rates of interest and terms for loans are established with the input of the consumer, of Alpha One, and the Finance Authority, the objective being to make loans as affordable as possible while maintaining the program's financial integrity.

This cooperation ensures that many consumers with limited incomes and meager assets qualify for assistance. That's very important.

6. The loan program can be the first means of financing assistive technology. However, this does not preclude a consumer from getting assistance through vocational rehabilitation or another public source for some of his financing needs with the balance being acquired through a low-interest loan. In fact, this strategy is often encouraged and has been highly successful.

7. The application process is time sensitive, requiring usually less than 1 month.

8. Most loans are collateralized with the equipment financed. If this is not practical, then personal assets like a savings account or the individual's residence, are used. Sometimes it is necessary for the applicant to have a co-borrower sign on the loan.

At this time, I want to share with you a few facts regarding Maine's loan program, which made its first loan in November of 1989. The figures which I will provide for you, are as of April 2, 1993.

As of that date, 242 loans had been closed. These loans amount to \$2,484,933. Forty-four loans have been paid off in the amount of \$210,792. The average loan size is \$9,211, the average interest is 4.8 percent, and the average term is 5.2 years.

Only seven loans—I want to emphasize this—only seven loans have been written off in the amount of \$3,158. I am not sure what the percentage is when you think of the amount loaned, but it was too small to calculate, so I did not bother.

Fifteen to 20 new loans are being processed each month.

Suffice it to say, many assistive technology projects have expressed an interest in developing a loan program like ours. In fact, 2 years ago, NIDRR gave Alpha One a grant to help assistive technology projects start loan programs.

Minnesota, Arkansas, Alaska, Vermont, North Carolina, and Utah are but a few of the projects we have helped.

Unfortunately, because this assistance came at a time when economies of States were suffering, the results were only fair. Nonetheless, Assistive Technology Act projects remain committed to this financing concept.

Now, should we encourage the development of more loan programs? If so, should these programs operate like Maine's, or should other models be encouraged?

How is oversight built into a loan program; how do we ensure a reasonable degree of equity if different models are pursued; and most important, how can the Federal Government act as a catalyst for the development of this alternative access mechanism?

Let me respond to the first question. Loan programs work, and there should be one in every State. Financing assistive technology through loans reduces the demand on public agency funding.

Furthermore, it helps the consumer develop self-esteem and a credit history, as well. This is a very significant system change.

These loan programs should be required to be in the private sector, whether they are like Maine's or utilize a different model.

Regardless of how they are structured, there should be strong and specific requirements for authentic consumer oversight. This oversight mechanism will ensure consumer responsiveness, help with disability sensitivity, and assist in creating a fair appeal mechanism.

If States choose to pursue different models, equity between these programs can be ensured through legislative mandates which will govern their development or could govern their development, administration, eligibility, and appeal procedures.

In an ideal environment, with unlimited funds, the United States Congress could appropriate money which States could acquire if they matched it with local funds. The level of Federal funding could be determined through a formula based on a State's population.

A more realistic approach, however, would be to establish a demonstration loan guarantee program similar to the VA or the FHA model with assistance from Alpha One if needed.

The demonstration program's objective would be to examine and define both the interest subsidy and guarantee levels needed to get commercial lending institutions interested in offering this type of financial assistance. The data from Maine's loan portfolio could expedite this process.

Also, the administrative structure which Maine's program employs could be studied to determine if a similar model could be replicated in a commercial lending environment.

A demonstration program, with \$15 million of new funding set aside to assist up to 10 States examine this model over the next three years, would have a big payoff.

A small amount of this money would be used to pay for technical assistance, while the bulk of it would be used to subsidize and guarantee loans made for the acquisition of assistive technology.

In my opinion, harnessing the resources of the private lending arena would be one significant way to assist consumers in meeting their needs for assistive technology.

The results of this demonstration would be shared with the Congress, NIDRR, the RESNA TA office, State-funded Assistive Technology Act projects, and other interested parties.

In closing, I strongly encourage you to appropriate new money in the reauthorization of the Technology Act for this purpose. I know it will bear results which will be a major component of the national solution needed to meet this challenge.

Thank you very much.

[The prepared statement of Steve Tremblay follows.]

STATEMENT OF STEVE TREMBLAY, PRINCIPAL INVESTIGATOR, ALPHA ONE, SOUTH
PORTLAND, MAINE

My name is Steven Tremblay. I am the founder and President of Alpha One, a center for independent living based in South Portland, Maine. The organization's mission is to develop and provide independent living opportunities for Maine's citizens with disabilities.

In 1988, the State of Maine undertook a bold initiative in the area of assistive technology. Following up on the recommendations of the legislatively established Independent Living Commission which I chaired, Maine voters were provided the opportunity through a statewide referendum to create a \$5 million revolving revolving loan fund for assisting individuals with disabilities, their families and private businesses in acquiring assistive technology.

The referendum question asked Maine voters the following: "Do you favor a \$5 million bond issue for the establishment of an Adaptive Equipment Loan Fund which would enable persons with disabilities to purchase adaptive equipment necessary to their independence?"

Maine voters responded overwhelmingly in support of this referendum and it passed with a 60-percent majority. At the time, with the exception of a few small public agency-based loan programs and one developed by the American Foundation for the Blind which financed one item of assistive technology only, experience with this financing strategy was unavailable.

At the outset our goal was to establish a loan program with a very specific philosophy. In my opinion, it is this philosophy which has made Maine's program so successful and, I should add, the envy of the Nation. Let me share with you the guiding principles which govern the program.

1. First and foremost, the program is consumer controlled. This criteria was assured by developing enabling legislation which required a consumer-controlled nine-member oversight Board. The governor nominates these individuals who are confirmed by the legislature. The consumers represent cross disabilities. Furthermore, the enabling legislation strongly recommended that the Board contract with a community-based organization experienced in assisting persons with disabilities to help with administering the program. In Maine's case, Alpha One was hired as this agent. The legislation also specified that Maine's Finance Authority would serve as

the fiduciary agent for this program. Both of these organizations have proved to be effective and efficient in co-administering this program.

2. The eligibility criteria outlined in the enabling legislation are simple and straightforward. These include the following: (1) a "qualifying borrower" means any individual, profit or non-profit corporation, or partnership which demonstrates that the loan will assist one or more persons with disabilities to improve their independence or become more productive members of the community, and (2) the individual or corporation or partnership must demonstrate creditworthiness and repayment abilities to the satisfaction of the board.

3. The loan program is for people with any type of disability. Also, it is available to private business which is especially important in light of requirements of the Americans with Disabilities Act.

4. As little as \$250 or as much as \$50,000 may be loaned to a qualified borrower.

5. Rates of interest and terms for loans are established with the input of the consumer, Alpha One, and the Finance Authority, the objective being to make loans as affordable as possible while maintaining the program's financial integrity. This co-operation ensures that many consumers with limited incomes and meager assets qualify for assistance.

6. The loan program can be the first means of financing assistive technology. However, this does not preclude a consumer from getting assistance through Vocational Rehabilitation or another public source for some of his financing needs with the balance being acquired through a low-interest loan. In fact, this strategy is often encouraged and has been highly successful.

7. The application process is time sensitive requiring usually less than a month.

8. Most loans are collateralized with the equipment financed. If this is not practicable then personal assets like a savings account or the individual's residence are used. Sometimes it is necessary for the applicant to have a co-borrower sign on the loan.

At this time, I want to share with you a few facts regarding Maine's loan program which made its first loan in November of 1989.

The figures as of April 2, 1993:

Two hundred and forty two loans have been closed.

These loans amount to \$2,484,933.

Forty-four loans have been paid off in the amount of \$210,792.

The average loan size is \$9,211.

The average interest is 4.8 percent.

The average term is 5.2 years.

Seven loans have been written off in the amount of \$3,158.

Fifteen to 20 new loans are being processed monthly.

Suffice to say many assistive technology projects have expressed an interest in developing a loan program like ours. Two years ago, NIDRR gave Alpha One a grant to help assistive technology projects start loan programs. Minnesota, Arkansas, Alaska, Vermont, North Carolina and Utah were but a few of the projects we helped. Unfortunately, because this assistance came at a time when States' economies were suffering the results were only fair. Nonetheless, Assistive Technology Act projects remain committed to this financing concept.

Should we encourage the development of more loan programs? If so, should these programs operate like Maine's or should other models be encouraged? How is oversight built into a loan program and how do we ensure a reasonable degree of equity if different models are pursued? And most important, how can the Federal Government act as a catalyst for the development of this alternative access mechanism?

Let me respond to the first question. Loan programs work and there should be one in every State. Financing assistive technology through loans reduces the demand on public agency funding. Furthermore, it helps a consumer develop self-esteem and a credit history as well. This is a very significant system change.

These loan programs should be required to be in the private sector whether they are like Maine's or utilize a different model. Regardless of how they are structured there should be strong and specific requirements for authentic consumer oversight. This oversight mechanism will ensure consumer responsiveness, help with disability sensitivity and assist in creating a fair appeal mechanism.

If States choose to pursue different models equity between these programs could be ensured through legislative mandates governing their development, administration, eligibility, and appeal procedures.

In an ideal environment with unlimited funds the United States Congress could appropriate money which States could acquire if they matched it with local funds.

The level of Federal funding could be determined through a formula based on a State's population. A more realistic approach, however, would be to establish a dem-

onstration loan guarantee program similar to the VA or FHA model with assistance from Alpha One. The demonstration program's objective would be to examine and define both the interest subsidy and guarantee levels needed to get commercial lending institutions interested in offering this type of financial assistance. The data from Maine's loan portfolio could expedite this process. Also, the administrative structure which Maine's program employs could be studied to determine if a similar model could be replicated in a commercial lending environment. A demonstration program with \$15 million of new funding set aside to assist up to 10 States examine this model over the next 3 years would have big payoff. A small amount of this money would be used to pay for technical assistance while the bulk of it would be used to subsidize and guarantee loans made for the acquisition of assistive technology. In my opinion, harnessing the resources of the private lending arena would be one significant way to assist consumers in meeting their needs for assistive technology. The results of this demonstration would be shared with the Congress, NIDRR, the RESNA TA office, State-funded Assistive Technology Act projects and other interested parties.

In closing, I strongly encourage you to appropriate new money in the reauthorization of the Technology Act for this purpose. I know it will bear results which will be a major component of the national solution needed to meet this challenge. Thank you.

Chairman OWENS. Thank you. Before you go—

Mr. TREMBLAY. I do not have to leave just this moment. I did not want to end up being caught short on the other side.

Chairman OWENS. Since default rates is an important item here, I just want to make sure I understood what you were saying. In Maine, seven loans have defaulted for about \$3,458 out of 240 loans which total \$2,484,000?

Mr. TREMBLAY. Precisely.

Chairman OWENS. I just wanted to make sure that the record has that clear. Thank you.

Our next speaker is Dr. Marvin Fifield, the Program Director, Utah State Program for Technology.

Dr. Fifield.

Mr. FIFIELD. Congressman Owens and Congressman Scott, I am very happy to be here.

I want to start with an apology. I had prepared my testimony on a floppy disk so that it could be read on Screen Writer for people that have vision loss, and I also prepared it in braille, but in my anxiety to get out of the snow of Utah and get over here into the sunshine of Virginia, I left it.

I make that announcement because I have it available, and I would be happy to distribute it in an alternate format if the people that are here would like to have that testimony.

Chairman OWENS. Thank you for the announcement. We will make certain that the committee makes it known that it is available if you will send it to us.

Mr. FIFIELD. I certainly will.

Utah was among the first nine States that was approved for a Title I project. In the 4½ years we have been in this, we have spent this time trying to implement a consumer-responsive statewide system. I might add that this has probably been the most exciting and rewarding time of my life.

The impact of the Assistive Technology Act must be more than just simply helping people get the assistive devices that they need. The legislation calls for the development and implementation of a consumer-responsive statewide program of assistive technology assistance.

Now, this requirement is a unique way of addressing the needs of people with disabilities. Just as technology changes our financial institutions and has changed our communications systems, assistive technology will change our human service systems.

Traditionally, we have focused our efforts on trying to fix a disability by finding a cure, rehabilitating, educating, or providing care. Assistive technology focuses on the environment, providing access to that environment or modifying the environment to accommodate the individual.

This paradigm shift from individual to environment was recognized in Congress in 1988. Title I activities of the Assistive Technology Act authorized many things that could be used as systems change, or they could also be used to provide and supplement services as usual.

The funding that is provided by the Assistive Technology Act is minuscule compared to the combined State and Federal funding that goes into education, rehabilitation, health systems, and our special disabilities programs. The only way that the Assistive Technology Act will have the envisioned impact is if these efforts are focused on changing the systems rather than providing just another strategy or treatment option.

It was with this in mind that Utah submitted their application emphasizing systems change rather than direct services.

In the appendix of my testimony, if you will turn past page 10—it is just at page 10—in Table I I have listed five indices of systems change. These were the activities that we focused on. That is in the first column of Table I.

The second column is the evidence of outcome or the results of 4½ years of attempting to change these systems, the activities we are funding, changing the funding streams, tracking equipment and changing policy.

The third one is interagency participation; the fourth is consumer participation in decisionmaking; the fifth is awareness training.

I am sure you will recognize that these are very similar to Virginia's systems change activity. I prepared this table for the purpose of showing the systems, indeed, can be changed, and we can measure these changes.

I believe it simply can be done, and we have not done it all. There is a lot more to do as you can see by the evidence that we have so far in Utah. State government is under a great deal of stress. Many States are cutting back their human service systems rather than expanding them.

Systems change, the kind that was envisioned by Congress in the Assistive Technology Act, does not come quickly and it will not come easily. A short-time stimulus of a little Federal money in assistive technology will not generate the systems change that we are asking for.

Furthermore, I do not believe that additional legal advocacy and asserting the rights of people with disabilities will obtain the desired change that we want in our system.

The benefits envisioned by the Assistive Technology Act will only come when our public service providers recognize that the needs of the consumer can more effectively or economically be provided

through assistive technology than a lot of the other techniques that were used in the past.

We will know when we have succeeded, when the priorities shift, when we reallocate funding and resources to facilitate assistive technology.

I believe that in order to accomplish that, we have to teach, we have to demonstrate, and we have to persuade the service agencies. Those are training activities.

Training can occur at many levels. It ranges from awareness training to very highly-refined professional skills and competencies. Congress recognized this and put training in the Assistive Technology Act in both Title I and in Title II.

With the exception of just a few hundred thousand dollars, virtually all of the money in the last authorization has gone into awareness-type training. We have very aggressively pursued awareness training, public awareness particularly. Virtually every State has undertaken awareness activities.

My point is that I submit, under the reauthorization, we must look beyond training at the awareness level; we must look at professional competencies and skills and training.

On the last page of my testimony I have a schematic chart that identifies four levels of training. It also identifies the population this training needs to be directed toward, and it suggests appropriate content areas.

To date, the emphasis has been on the bottom two tiers, the bottom-most of that pyramid. This is awareness and familiarity training. In the reauthorization, we must shift to skills training as the primary focus, particularly of Title II.

After we had been in the program for 2 years, we became aware in Utah that the consumers were better informed about available technology and the benefits that it provided than the providers.

We found that consumers were more eager to learn about technology. We found many of our providers, who we attempted to train, to be technologically illiterate. Some of them were technophobic.

Even those that claimed to be knowledgeable and literate, only knew about technology in very narrow areas of systems and devices.

We tried to offer classes in special education, communicative disorders, occupational and physical therapy, rehabilitation and about assistive technology, and we could not find faculty members that could teach those courses.

Other Title I State programs have experienced almost the same thing. I believe all 42 of the funded States have found that it has been extremely difficult, and in some cases impossible, to find adequately skilled and trained staff for our own programs.

Our universities are turning out thousands of special educators and speech language specialists without even basic exposure to the available technology that they should be working with.

Occupational and physical therapists, who are graduating, know only about the technology that they use on a day-by-day basis. They know nothing about computers, language systems, job accommodations, or low-vision technology.

Unless we are willing to continue to just learn on the job or take trial-and-error learning, we must be ready to invest in professional training in a significant way.

We need long-term assistive technology training programs that will include interdisciplinary experiences in working with consumers, where they evaluate needs and they modify and customize technology to meet those needs. This training must be provided in an environment where consumers are active participants in all decisions.

To provide this type of training, we have got to look beyond just the resources of the Assistive Technology Act. I recognize this.

In the Individuals with Disabilities Education Act, the personnel preparation section alone provides over \$80 million for training. That Act needs to be amended to include assistive technology.

The new Rehabilitation Act has a large amount of money—more money than in the Assistive Technology Act—for long-term training. We need to amend those acts so they will include the training of occupational and physical therapists and other personnel so that they are technologically literate.

Providing assistive technology requires the experience and expertise of engineers, computer scientists, and manufacturers, as well as skilled craftsmen and technicians in electronics and fabrication. Currently, there is virtually no systematic training for these disciplines. This is where I think the Assistive Technology Act needs to step in.

Last year, Utah State University was funded for a small program out of Title II for an assistive technology careers demonstration training program to address this very need.

We provided stipends for 16 seniors who were training to be engineers; industrial technologists; computer scientists; and communicative disorders, rehabilitation, and special education personnel.

These undergraduate seniors were brought together in teams. They received nine university credit hours for a year-long course. It has 4 more weeks to finish up this year.

The course included didactic training where they learned about the nature of disabilities, human service systems, and various disciplines. The important part was the practicum—the hands-on experience of working with consumers—actually designing, fabricating, and changing devices, and finally, arriving at assistive technology solutions.

At this point, each of these 16 trainees are working on several technology projects. They are designing, fabricating, and customizing their adaptive technology.

Several are using assistive technology as their senior research project, and we are entering two of these designs into the National Science Foundation competition.

The results of this 1-year experience have been nothing short of spectacular. The engineering and computer science students, we found, are delighted to be able to use their technology skills to meet a real human service need.

By focusing on seniors, stipends can be very small. They will accept almost anything to keep in school. We can accept more students that way.

This is before seniors have made their commitments to careers, so they can be recruited into rehabilitation engineering and assistive technology fields.

Even those whose career choices include building our bridges, building our space shuttles, program computers, or working on weapons systems, I believe will be highly influenced by this interaction that they have had in this year-long project.

Throughout their lives, with each new invention or each new technology device in which they come in contact, they will view them as potential assistive devices, and every time that they interact with a person with a disability, I believe their thoughts will return to how their technical skills can help that person in this ever-expanding field of technology.

This was a first-toe-in-the-water approach to a very critical training need. In the reauthorization of the Assistive Technology Act, we must strengthen Title II and focus on higher-level training.

There is also a need for special institutes to provide training to university faculty. This is the quickest way that we can establish the pre-service training that is needed for many of the disciplines that require a knowledge of technology.

We need to develop materials and in-service training for people that are already providing services, and we need to do something about the licensing and the certification requirements so that assistive technology competencies and skills are included.

Let me summarize my testimony by making four recommendations concerning the reauthorization of the Assistive Technology Act. You will recognize that these are very close to what Ken presented for Virginia.

I recommend that Title I reauthorization be extended an additional 5 years, permitting States to continue the activities and establish a consumer-responsive statewide program for technology-related assistance.

I recommend that continued funding for Title I be competitive, not on a formula; that it be based on evidence of progress.

I recommend that the activities authorized under Title I focus on systems change and, as was testified by Ken, that benchmarks of progress be identified and monitored.

I recommend that Title II be expanded to authorize a variety of assistive technology careers training projects; that these focus on specialized training; and that we include undergraduates, assistive technology training for engineers, computer scientists, and design personnel. This should include training of technicians in fabrications, electronics, and computer techniques. Special institutes should be authorized for assistive technology leadership training.

In conclusion, no human service can be any better than the training of the people to provide that service. The best assistive technology in the world, well financed and made universally available, will not be successful unless those people providing the technology, have the competencies and the skills to determine need, to identify appropriate technology, and to adapt it to meet those needs.

Thank you.

[The prepared statement of Marvin Fifield follows.]

Reauthorization of P.L. 100-407

**Testimony Submitted to
The House Subcommittee on
Select Education and Civil Rights
Major Owens, Chairperson**

by Marvin Fifield

Congressman Owens and Committee members, my name is Marvin Fifield, and I direct the Utah Assistive Technology Program. Utah was among the first nine states approved for a Title I project. Thus, the past four years, have been spent implementing a consumer-responsive, statewide system of assistive technology in Utah. I might add that this has been among the most exciting and rewarding experience in my life.

The impact of P.L. 100-407 must be much more than simply helping persons with disabilities obtain assistive devices. The legislation calls for the development and implementation of a consumer-responsive, statewide program of technology-related assistance. This requirement is a unique way of addressing the needs of persons with disabilities. Just as technology has changed our financial institutions and communication systems, assistive technology will change our human service systems.

Traditionally, we have focused on fixing disabilities by finding cures, rehabilitating, educating or providing care. Assistive technology focuses on the environment: providing access or modifying the environment to accommodate the individual. This paradigm shift from individual to the environment was recognized by Congress in 1988. Title I of the Tech Act authorized a variety of systems change activities. However, many of those authorized

activities can be used either to change a system or to provide support and supplement services as usual.

The funding provided by the Tech Act is minuscule compared to the combined state and federal funding for education, vocational rehabilitation, health systems, and special disability programs. Thus, the only way the Tech Act will have the envisioned impact is if efforts are focused on changing systems, rather than providing just another strategy or treatment option.

Systems Change

With this in mind, Utah's Title I application emphasized systems change rather than direct service. Selected activities were designed to make changes in Utah's public and private service systems. Activities included (a) expanding the number and the size of funding streams for assistive technology, (b) resolving policy and procedure barriers, (c) placing consumers into the decision making process of agencies at all levels, and (d) bringing the assistive technology efforts of different services agencies together to enhance peer pressure and stimulate needed change.

We feel good about the changes we have been able to influence. Most significantly, we feel that these changes will have an accumulative effect in the years to come.

Appended to my testimony in Table I are five indices of systems change. In the second column are outcomes evidence of system change in each of these areas. As the table

indicates, we still have much to do in Utah before we have a consumer-responsive, statewide system of assistive technology services.

State government is under a great deal of stress. Many state human service programs are cutting back rather than expanding because states do not have the money to match available federal funds.

Systems change, the kind envisioned by Congress in the Tech Act, doesn't come quickly nor easily. A short time stimulus of a little federal money in assistive technology is not going to generate the systems change or the benefits envisioned. Furthermore, I do not believe that additional legal advocacy and asserting the rights of people with disabilities will obtain the desired changes we need in our service systems.

Benefits envisioned by the Tech Act will only be realized when public service providers recognize that the needs of consumers can be more efficiently and economically met by providing assistive technology devices and services than by many of the techniques that have been used in the past. We will know that we have succeeded when public service agencies change priorities and allocate funding and other resources to facilitate assistive technology services. To accomplish this we have to teach, demonstrate, and persuade. These are training activities, and it is to this area that I would like to turn.

Training

Training can occur at many levels ranging from simple awareness to highly refined professional skills and competencies. Congress recognized the need for training in the Tech

Act. Title I of the Act authorizes public awareness training and information dissemination. Part C of Title II of the Act also authorized training and public awareness. However, with the exception of a few hundred thousand dollars, virtually all of the funding provided for training by the Tech Act has been focused at the awareness level. Title I states grants have public awareness activities to acquaint consumers with the benefits of assistive technology. Also, at the awareness level, information and referral systems have been established, and public awareness campaigns undertaken.

We now have had four and one-half years of aggressive public awareness activities. Although progress has been made, awareness training should continue as the training theme of Title I. However, I submit that under the Tech Act reauthorization we must look beyond training at the awareness level. We must address professional competencies and skills training.

Table II appended to my testimony presents a schematic identifying four levels of training, the population to which this training is directed, and suggested appropriate content areas. To date, the emphasis has been on awareness and familiarity. In the reauthorization, emphasis must shift to skills training as the primary focus of Title II.

Following two years of aggressive consumer training and public awareness programs in Utah, we became aware that consumers are better informed about available technology and its benefits than providers. Furthermore, we found consumers more eager to learn about technology than many providers.

Many providers we attempted to train were found to be technologically illiterate or technophobic. Many actively resisted technology in any form. Even those who considered themselves technologically literate were knowledgeable in such narrow areas of devices, services, and options that they could only provide limited assistance to consumers.

We tried to offer assistive technology classes in special education, communicative disorders, occupational and physical therapy, and rehabilitation. However, we could not find faculty who could teach such courses. Other Title I state programs had this same experience. We have all found that we could not find adequately skilled or trained staff for our own programs.

Our universities are turning out thousands of special education and speech and language specialists without even basic exposure to the available technology. Occupational and physical therapists are graduating who know nothing about computers, language systems, job accommodation, or low vision technology.

Unless we are willing to continue to learn on the job, or by trial and error, we must be ready to invest in professional training in a significant way. Long-term assistive technology training programs are needed which include interdisciplinary experiences in working with consumers, evaluating their needs, and modifying and customizing technology to address those needs. This training must be provided in an environment where consumers are active participants in all decisions.

To provide this type of training we must look beyond the resources of the Tech Act. Assistive technology training for teachers and speech and language specialists should be

provided by the personnel preparation provisions of the Individual with Disabilities Education Act (IDEA). Assistive technology training for rehab personnel, including counselors, OTs, and PTs, should be included in the long-range training of the Rehabilitation Act and the Health's Professional Training Act. I urge the Committee to consider amending these acts to authorize needed assistive technology training.

But this isn't all. Providing assistive technology requires the expertise of engineers, computer scientists, and manufacturers, as well as the skills of craftsmen and technicians in electronics and fabrication. Currently there is virtually no systematic training for these disciplines.

Last year Utah State University was funded through Title II of the Tech Act for a model Assistive Technology Careers Demonstration Training Program. We are just completing the first year of this program. The program provided small stipends for sixteen senior year students in engineering, industrial technology, and computer science. We also included graduate students in communicative disorders, special education, rehabilitation, and social work. These students were brought together in interdisciplinary assistive technology teams. Each trainee received nine hours of university honors credit for a year-long course of study which included:

- (1) **Didactic Instruction.** Seminars provided information about the nature of disabilities, the human service system, the role of various disciplines, and sources of information about technology.

- (2) **Practicum.** The practicum included hands-on experience working as team members in the community with assistive technology service agencies assessing consumer needs and arriving at assistive technology solutions.

At this point each trainee has several assistive technology projects underway. They are designing, fabricating, customizing, or adapting technology to meet the needs of the persons with disabilities. Several are using assistive technology for their senior research project, and we are entering two in the design competition of the National Science Foundation.

The results of this one-year experience has been nothing short of spectacular. Engineering, computer science, and students in other technology disciplines have been thrilled with the opportunity to use their technological skills to meet a real human need. By focusing on seniors, stipends can be very small, and we can accept more students. As seniors, career commitments are still open, and they can be recruited into graduate work in rehabilitation engineering and assistive technology fields such as ergonomics.

Even those who choose careers where they build bridges, space shuttles, design or program computers, or work on weapon systems will be highly influenced by the personal interactions and the projects they have designed, customized or modified to meet the needs of people with disabilities. Throughout their lives, each new invention or technology they work with will be viewed as a potential assistive device. Each time they meet or interact with a person with a disability, their thoughts will return to how their technical skills and their knowledge can meet the needs of that person in the ever-expanding field of technology.

The Utah State University Technology Career Project is a first toe-in-the-water approach, taken to meet a critical training need. In the Reauthorization of the Tech Act, we must strengthen Title II and focus on higher level training. Training provisions that need to be added include special institutes to provide training to university faculty. This is the quickest, most effective method of impacting the preservice training that is critically needed. Workshops, special training institutes, and materials for inservice training of the service agency staff currently providing these services must be expanded. Licensing and certification requirements must be modified and improved to ensure that service providers are assistive-technology literate at all levels and can demonstrate the competencies and skills necessary for assistive technology specialization.

Let me summarize my testimony with four specific recommendations for consideration in reauthorizing the Tech Act:

1. I recommend that Title I authorization be extended an additional five years, permitting states to continue the activities which will establish a consumer-responsive, statewide program for technology-related assistance.
2. I recommend that continuous funding for Title I be competitive and based on evidence of progress.
3. I recommend that activities authorized under Title I be focused on systems change, and benchmarks of progress be identified and monitored.
4. I recommend that Title II be expanded to authorize a variety of assistive technology career training projects. These projects should focus on

specialization training and include undergraduates, AT training for engineers, computer scientists, and other design personnel. They should include training of technicians in fabrication, electronics, and computer techniques. Special institutes should also be authorized for assistive technology leadership training to meet the needs for administrators, researchers, and teaching personnel.

No human service can ever be better than the training of those who provide the service. The best assistive technology that we can provide, finance, and make universally available will have pale success unless those providing this technology have the competencies and the skills to determine need, identify appropriate technology, and adapt it to address these needs.

Table I
**Assistive Technology Indices of Systems Change
 and
 Evidence of Systemic Change in Assistive Technology
 Devices and Services in Utah**

19 April 1993
 Marrin G. Fifield, Ed.D.

The Utah Assistive Technology Program (UATP) is currently in its fourth year of support from Title I of P.L. 100-407 "Tech Act". The long-range approach taken by UATP was to effect needed change in Utah's service delivery system to expand significantly the use and maintenance of assistive technology by persons with disabilities to obtain independence, integration, and productivity. The first three years of Tech Act assistance focused on AT awareness of consumers and providers. Baseline descriptive data on need, existing services, funding, and procedural barriers. The following elements were implemented: (1) The Funding and Legislation Policy Unit, (2) Information & Referral System, (3) Four Assistive Technology Access Centers, and (4) The Awareness and Training Unit. The two-year extension grant program focused on implementation of needed AT service elements to expand and improve the AT services provided in the state. The implementation plan included provisions for state agencies to "buy-in" and take over these new service elements during the two-year period. To ensure that change and improvement in AT services are continued after the termination to the Tech Act funding.

On the Table below, five indices of assistive technology systems change are identified. In the second column, evidence in changes which have occurred in each of the indices in Utah is presented.

<u>Indices of Systems Change</u>	<u>Outcome Evidence of Systemic Change in Utah</u>
1. Increase in funding for assistive technology	
a. Increase in state funding	<p>An additional state appropriation of \$380,000 was allocated by the state legislature to purchase assistive technology through the independent living centers in 1991-92-93.</p> <p>An additional \$55,000 was allocated by the state legislature in 1993.</p> <p>An additional \$150,000 was allocated by the 1993 legislature as match for Medicaid to purchase power wheelchairs for adults. This represents approximately \$450,000 in additional AT funding.</p>
b. Increase in alternative sources of funding	<p>The Utah Assistive Technology Project has established the Utah Assistive Technology Foundation (UATF) a private, non-profit, philanthropic organization responsible to obtain, through donations from individuals, service organizations, or other sources. Funds obtained are to be utilized to purchase assistive technology through direct grants, loans, or loan guarantees.</p>

Indicators of Systems ChangeOutcome Evidence of Systemic
Change in Utah

c. Increase in existing funding streams that include assistive technology	For the past four years, the Utah Legislature has increased the state funding provided to the Department of Health, Vocational Rehabilitation, Human Services, and Special Education. These increases have ranged from 2% to 4%. During the last two years, the need for assistive technology was used as a justification when the agencies presented their budget requests. Funding, specifically for assistive technology, was not broken out from other services. However, there has been clear evidence that a significant portion of increase in funding has been directed to the purchase of assistive technology by each of the agencies.
d. Changes in assistive technology funding policies	Three specific changes have occurred to improve AT funding policies: (1) An interagency memorandum of agreement concerning the importance of technology in the lives of persons with disabilities and responsibilities has been approved. (2) Change which permitted unused funds to be redirected as match to medicaid to purchase assistive technology. (3) The \$150,000 increased appropriation to Health Care Financing carried with it a change in policy permitting Title 19 funds to be used to purchase AT. UATP has established an Interagency Policy Task Force to develop clear policies concerning assistive technology eligibility, funding, definitions, and procedures.
2. Indicator of Systemic Tracking of Assistive Technology Funding of Devices and Services	
a. Defendable and comparable information from state service agencies on what is being spent on AT services and devices	At the beginning of the UATP, Utah service agencies did not track or identify funds spent for assistive technology. AT funding was grouped with other items such as durable medical equipment, teaching supplies, or client services. Efforts to break out specific reporting techniques that provide comparative information on dollars spent, services provided, or devices obtained, have been difficult to finalize. This year the Division of Rehabilitation Services has established a procedure to report assistive technology purchased, dollars spent, services provided, and devices obtained. Comparing this data to a year ago, significant expansion has been evidenced.

Table 1 (continued)

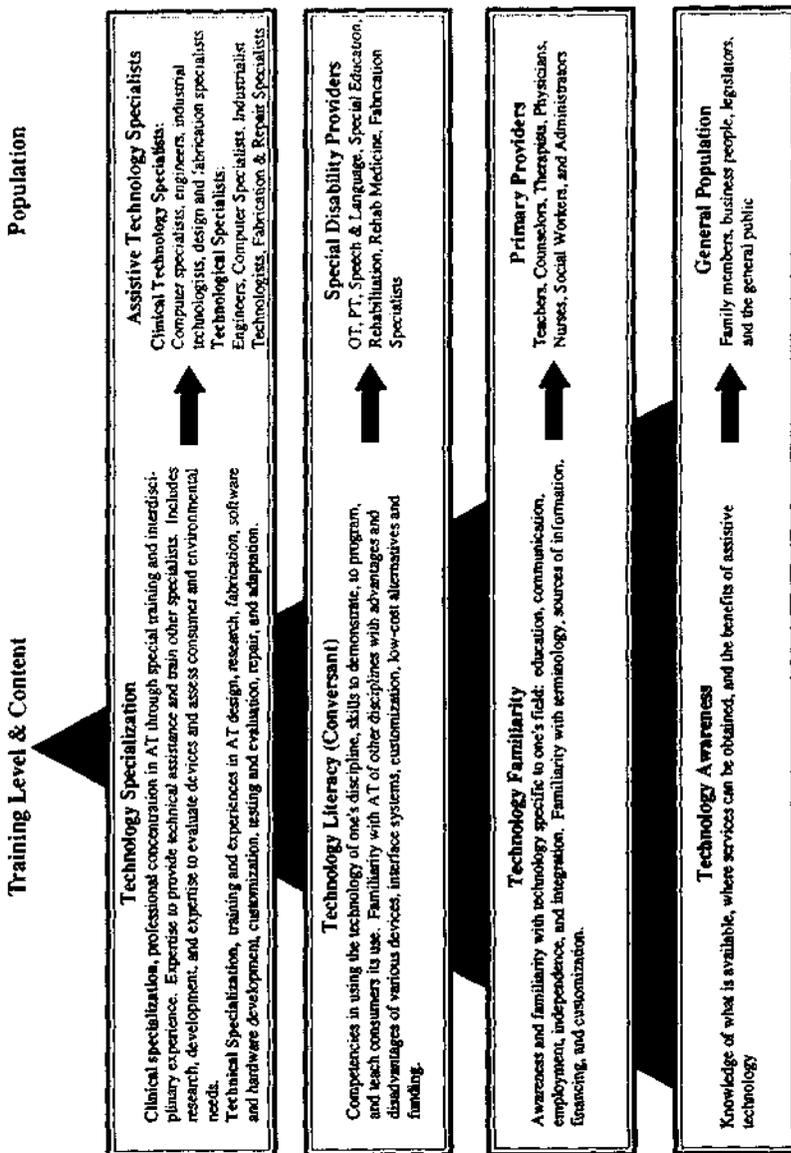
Indicators of Systems ChangeOutcome Evidence of Systemic Change in Utah

b. Removal of policy barriers (definitions, eligibility criteria, appeals process, and clear decision points)	With the publication of the Utah Assistive Technology Funding Guide, participating agencies had to identify their policies, definitions, and decision procedures for purchasing assistive technology. Through this process, several policy barriers were identified and removed. Others were identified, but remain to be significantly modified.
3. Interagency Participation	
a. Interagency participation in the AT Title I project	The UATP is managed by a Board consisting of the Directors of the six major service agencies: Special Education, Vocational Rehabilitation, Family Health Services, Health Care Financing, Division of Services for Persons with Disabilities, and Division of Aging.
b. Commitments and pooling of funds from each agency for expanding AT services	Currently, state agencies are providing approximately one-half of the operating costs of the AT information and referral program (\$60,000). Requests for pooling of resources from participating agencies for an assistive technology assessment unit are under consideration.
c. Pooling of commitment of department staff to improve AT services	Commitments of state agency staff work in an interagency assessment unit is under consideration.
d. Commitment to training	Interagency AT training has not been adequately addressed; however, VR counselors and assistive technology counselors from the independent living programs have participated in training provided by the special education, assistive augmentative, and adaptive service teams. Additional training projects have been initiated, two in Assistive Technology Careers Training two to develop training modules in assistive technology.
4. Consumer Participation	
a. Consumer participation in management and direction of the Title I project	Consumer representation controls the votes of the UATP Management and Implementation Board. Also, the consumers maintain a veto power, similar to the Security Council in the U.N. In addition, a Consumer Council has been established consisting of all consumers. The Consumer Council deals with consumer issues and makes recommendations to the M&I Board, which must be responded to in writing.

Table I (continued)

<u>Indicators of Systems Change</u>	<u>Outcome Evidence of Systemic Change in Utah</u>
b. Consumer participation in key state agencies	The UATP Consumer Council and M&I Board have established a model of consumer participation being implemented in other key state-wide policy and advisory bodies. UATP bylaws of the M&I Board and the role description of consumer members are being used as models for other state agencies.
c. Key service agency commitment to empowerment of consumer participation	At the instigation and the UATP Board, the Governor's Council for Person's with Disabilities has undertaken the development of a position statement on consumer participation and empowerment for statewide governing boards, committees, and advisory bodies. This position statement will include recommendations concerning support for consumer members, empowerment, and training of consumer members.
5. Awareness and familiarity with AT and AT services	<p>To evaluate the impact of UATP, systematic interviews were scheduled with approximately 300 randomly selected consumer members at periodic times during the five years of the grant. The data obtained from these interviews clearly reflects an increase in the familiarity of providers and consumers with the value of assistive technology, how assistive technology is defined and where AT services can be obtained.</p> <p>UATP also analyzes the questions and the information sought by consumers from the AT information referral center. This data suggests increased sophistication in the awareness of assistive technology, benefits, and where services may be obtained. It also indicates increased frustration on the part of consumers in obtaining AT funding.</p>

Table II
**Technology-Related Assistance Act:
 Training Issues**



Chairman OWENS. Thank you.

Mr. Girish Yajnik.

Mr. YAJNIK. Chairman Owens, Congressman Scott, and other members who are not here, on behalf of the Center for Developmental Disabilities at the University of South Carolina, I am very honored—and I offer my gratitude to this committee—to have this unique opportunity to discuss the findings of our research study on the feasibility and the desirability of establishing a national information and a program referral network.

As many of you are aware, in the fall of 1991 we were awarded a contract to conduct an 18-month study under the authority of Public Law 100-407, administered through National Institute on Disability and Rehabilitation Research.

This was an 18-month study, and it is a tall order to summarize the work of 18 months in 5 to 7 minutes, so I have actually provided a summary in my testimony, and I do not intend to—

Chairman OWENS. You are not limited to 7 minutes.

Mr. YAJNIK. Okay. That was the guideline I was given.

So, I am going to touch upon the highlights, and I am here to answer questions, to elaborate on any particular issues you may have, sir. Please stop me at any moment if I am glossing over anything or if you need more information.

This study explored the feasibility of establishing a national assistive technology information program referral network, which we will address as I&R network, from two differing perspectives: one, the current processes used to disseminate information about assistive technology and, two, the needs of individuals who want to access assistive technology information.

We investigated the essential mechanism to link information on assistive technology with the individuals who need it.

The challenge of providing accurate, timely, and quality assistive technology I&R is still ahead of us as a society.

New opportunities face the I&R field with advances in information technology every day. These advances in the electronic communication field through worldwide networks, teleconferencing, use of multimedia, and computers will make managing complex information increasingly easier.

This is the right time to apply innovative technology to merge the needs of service delivery systems and the information requirements of people with disabilities.

Currently, there is an information network of nationally-funded programs, State Assistive Technology Act-funded initiatives, and other similar local information resources.

However, as a functional system, we found that it is not very effective because the majority of the information programs are uncoordinated, fragmented, and sporadic efforts.

Further, as a system of care for people with disabilities, it certainly does not provide full assurance that useful information will systematically reach consumers and other information seekers.

Not surprisingly, this study's major conclusion was that not only is it necessary and desirable, but it is also feasible to establish a national assistive technology information and program referral network.

Before I move on to the key findings of our study, let me add some of the comments from a colleague who represents a major national disability organization.

She corroborated our findings that I&R programs are labor-intensive, requiring significant staff resources to compile, catalog, and maintain information and ensure the integrity of the database of information and provide the personal attention necessary to meet the needs of individuals requiring assistive technology information.

Typically, the cost of assistive technology I&R must be absorbed by the entity providing the service. Because there are currently no consistent funding mechanisms to support these activities, providing accurate information is a critical component in the process of acquiring assistive technology. Yet, it is not so highly valued, because it is often difficult to determine whether I&R has had a direct impact on the individual to secure the appropriate device or service.

She also added that the demand for information is so great that individuals providing the service are often overwhelmed—and I would like Mark to address that when he provides his testimony—by the volume or the complexity of the request, making it difficult to take additional time necessary to document the true cost of providing this service or ways to evaluate the quality or value of the service and information provided. This contributes to lack of uniformity and consistency of these programs identified in the study.

These variations, and the fact that assistive technology I&R programs lack adequate resources to improve or expand their services, puts these programs at risk and underscores the need to seriously consider the recommendations and conclusions provided by our report.

I would like to briefly summarize—and I am not going to read everything that is in my testimony. I have found out lately that we have compiled several reports that are available to people who would like to study them. Most of the people who are reacting to our study have read only one part or maybe a portion of our reports.

I have listed the deliverables of our research study at the end of my testimony, and these are available in alternative media for those people who may wish to request them. I will be glad to provide them if needed.

The key issues we identified concerning the establishment of a national assistive technology information program referral network were quite similar across geographic areas, segments of population, and service needs.

I would like to add that what we found was not too different. Everybody was struggling to develop their own information program.

We studied all the funded assistive technology programs that have development or operation of an information referral system within their State to see to what degree the development has progressed and to assess their needs. A lot of our recommendations are based on that. Let me point out some of the things that we found.

Number one, assistive technology information and program referral services are not uniformly defined. What do I mean by that? Well, services differ from program to program. The number of serv-

ices covered within an I&R program differ. Some emphasize one segment of services as opposed to the other.

Lack of coordination of information referral services across community, State, and regional and national levels: We found no evidence that any one program knew about other programs that existed.

Population and geographic area served differ from program to program; access to service differs and may not be reflective of the target service population and their accessibility needs; and the term "assistive technology" may differ between service provider and the target population who can benefit from this service.

Number two, the organizational structure of assistive technology information program and referral services are not uniform from program to program.

Number three, training for assistive technology information and referral programs was flawed; there is a lack of standards and/or requirements for the assistive technology I&R staff. Again, I support Dr. Fifield and would like him to add to his training needs a component related to I&R programs. Training is a major component of providing I&R services.

Number four, information management is flawed by lack of consistent methods to obtain, verify, and update information. You will see a lot of programs that say they have lots of information, but how good is it? What impact does it make when they deliver that information to consumers? What difference did it make to those people? Did they get the service or the assistive device that they were looking for; did they find the funding information?

Also, there are so many good programs out there but not many people know about them. Outreach efforts to the target population are pretty much ineffective and/or nonexistent. When asked, consumers state that they find assistive technology I&R programs, many times, by accident. There is no structured method of reaching various populations.

We have made many recommendations to be included in the reauthorization, and we hope that you will keep these in mind as you reauthorize the Act.

One of the major—and I am just going touch upon the major one—recommendations that we made was with regards to policy and coordination of I&R services.

Right now, there are a lot of programs operating independently. There is a lot of duplication of effort.

A lot of I&R programs are finding out that they have invested a significant amount of time and effort in doing things, only to find out a year or a year-and-a-half later that they could have avoided a lot of pitfalls if they had talked to somebody who had already done this. Therefore, we are recommending that NIDRR provide leadership to develop a national assistive technology information and program referral coordinating institute.

This initiative will provide the needed training, technical assistance and support to regional, State, and local information programs. NIDRR, probably along with the RESNA TA project, should provide the oversight for the activities of this coordinating institute. The activities should include the following:

Facilitate an orchestrated approach to delivery of assistive technology I&R services; provide technical support to assistive technology I&R services as requested or needed by the various States and local programs; develop a technical assistance manual for coordination of assistive technology I&R services which details strategies within the context of the options available to deliver I&R services; develop generic training manuals to enhance the delivery of assistive technology I&R services and begin to address the information referral quality standards; provide training to enhance the capacity of the I&R staff to deliver assistive technology I&R services; develop and implement a plan for a fully coordinated assistive technology I&R delivery system with centralized functions providing technical support needed by community assistive technology I&R services.

Some of the other recommendations are: develop a national classification schema or taxonomy of delivery of assistive technology I&R services that integrates well with other existing service delivery taxonomies.

Many of those exist today, and unless we have some degree of uniformity, transfer of information from various systems is the greatest impediment. Therefore, we are suggesting that we arrive at a common terminology so we are talking about the same things and not apples and oranges.

We also heard a lot from consumers who say that when they have a need to move from one State to another, they do not know how to contact or how to find out what assistive technology services are available in various States.

Therefore, we are suggesting that, until such time when State and local information programs have the capacity to meet the regional information needs, we establish a national assistive technology I&R toll-free number that works in tandem with the existing programs to link persons with disabilities, the assistive technology services and providers with appropriate resources at the national, State, or regional levels.

This service must be accessible in a variety of formats and provide linkages to referral at the local and State levels.

We also suggest the development and implementation of initiatives that recognize the value of I&R services and build support for a coordinated system.

Today, I&R has very low priority, and there is no designated funding available. Whatever funds are left over, every program assigns to I&R. We need more attention focused on I&R.

We also suggest convening a national meeting of Federal agencies to develop strategies designed to help coordinate and improve delivery of I&R services; this meeting can result in identifying a national assistive technology information and program referral task force to develop strategies for improved interagency coordination of technology-related services. This task force should include representatives from consumer groups, professional associations, public sector agencies, private non-profit agencies, and I&R practitioners.

This initiative should examine ways to capitalize emphasis on the use of computers and other similar technologies, and on evolving technologies in other disciplines and should involve allied agen-

cies such as NASA, Office of Technology Transfer, and other similar agencies.

We also propose that we conduct field-initiated research of I&R best practices and the application in the dissemination of assistive technology information.

Finally, establish a national assistive technology evaluation project to provide indicators to help consumers determine the quality and applicability of services and devices in meeting the technology needs.

I have identified many other recommendations, but in interest of time and allowing others to ask questions, I am going to omit those and let the committee look them over.

I would like to add that all our recommendations are based upon a statistically validated representative population. There are some stated limitations. However, these are not statistically significant to make an appreciable difference.

Our research was very thorough, and the approach used was divided into five components, which I have listed. We had 16 individuals from the assistive technology I&R who were in our expert panel group. They provided input into the overall design of the research, reviewed the findings, and contributed to the final recommendations of the study.

We also conducted a key informant survey. We had 541 assistive technology I&R providers. We assessed them, their current State of practice, how they were providing information, and what they thought about establishing a national assistive technology information and program referral network.

We also conducted a survey of 4,298 individuals that determined the assistive technology I&R needs. Approximately 100 persons with disabilities were from underrepresented groups not found in the survey. We had 62 individuals that we polled through regional focus hearings—we had four of them—and then we identified some of the technical barriers.

Again, I would reemphasize that anyone who wants to examine or review our research with all the deliverables, or all five reports that we have compiled, should study them carefully before arriving at any conclusion.

In conclusion, I would like to reiterate the sentiments of many who helped us with this research: that the establishment of a national information and program referral network would be an essential catalyst to make other assistive technology programs more efficient and effective.

We would be very happy to provide additional information or clarification and entertain any inquiries about this research study.

On behalf of the staff, I am very honored for this opportunity to provide testimony to this distinguished group.

Thank you very much.

[The prepared statement of Girish Yajnik follows.]

Executive Summary

This document was prepared under contract #HN90053001 from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, to the Center for Developmental Disabilities at the University of South Carolina. The contents of this publication do not necessarily reflect the views or policies of NIDRR. No official endorsement by the U.S. Department of Education is intended or should be inferred.

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Testimony to the Subcommittee on Select Education and Civil Rights
 At the Request of U. S. Representative Hon. Major R. Owens
 Chairperson, Committee on Education and Labor
 April 19, 1993

*Discussion of the Findings of the Study on the Feasibility and Desirability of
 Establishing a National Information and Referral Network for Assistive
 Technology.*

Mr. Chairman Owens & Members of this Subcommittee:

On behalf of the Center for Developmental Disabilities at the University of South Carolina, I am honored and offer my gratitude to this committee to have this unique opportunity to discuss the findings of our research study on the Feasibility and the Desirability of Establishing a National Information and Program Referral Network. As many of you are aware, in the Fall of 1991 we were awarded a contract to conduct this 18 month study under the authority of Public Law 100-407 administered through the National Institute on Disability and Rehabilitation Research (NIDRR).

This study explored the feasibility of establishing a national Assistive technology information and program referral (I & R) network from two differing perspectives:

- the current processes used to disseminate information about Assistive technology, and
- the needs of individuals who want access to Assistive technology information.

We investigated the essential mechanisms to link information on Assistive technology with the individuals who need it. The challenge of providing accurate, timely, and quality AT I & R information is still ahead of us as a society. New opportunities face I & R field with advances in the information technology arena. These advances in electronic communication field through worldwide networks, teleconferencing, use of multimedia and computers will make managing complex information increasingly easier. This is the right time to apply innovative technologies to merge the needs of service delivery systems and information requirements of people with disabilities. Currently an information network of nationally funded information programs, state Tech Act funded initiatives and other similar local information resources does exist. However, as a functional system, it is not very effective because majority of information programs are un-coordinated, fragmented and sporadic efforts. Further, as a system of care for people with disabilities, it certainly does not provide assurance that useful information will reach systematically to consumers or information seekers.

Not surprisingly, this study's major conclusion was that not only is it necessary and desirable, but it is also feasible to establish a national Assistive technology information and program referral network.

SUMMARY OF KEY FINDINGS

This testimony provides a summary of the study findings. Readers should examine the other reports for a more complete understanding of the issues affecting the Feasibility and Desirability of Establishing a National Assistive Technology Information and Program Referral Network.

The key issues identified concerning the establishment of a National Assistive Technology Information and Program Referral Network were similar across geographic areas, segments of the population, and service needs. *The study documented the following technical factors as affecting the Assistive technology information and program referral process:*

1. **Assistive technology information and program referral services are not uniformly defined:**
 - Services differ from program to program;
 - Lack of coordination of information and referral services across community, state, regional, and national levels;
 - Population and geographic area served differ from program to program;
 - Access to the service differs and may not be reflective of the target service population or their accessibility needs; and
 - The term "Assistive technology" may differ among service provider(s) and the target population who can benefit from the service.

2. **Organizational structure of Assistive technology information and program referral services are not uniform from program to program:**
 - There is a lack of guidelines for staff patterns and requirements for AT I & R staff;
 - There is a lack of standards to guide the confidentiality of consumer information obtained by agencies in the provision of information services;
 - There is no apparent correlation between budget allocation and services and/or quality of service; and
 - Responsibilities of AT I & R staff differ from program to program.

3. **Training for Assistive technology information and program referral staff is flawed by the lack of standards and/or requirements for AT I & R staff:**
 - Assistive technology information and program referral staff are not traditionally trained to deliver AT I & R services but, rather, to respond to the limited information requests of a particular database or written publication;
 - The whole-person concept is often not employed or not existent, with the emphasis placed on responding only to a specific request for a device; and

- There is a heavy reliance on written materials and time-dated databases where the information may or may not be accurate.
4. Information management is flawed by the lack of consistent methods to maintain, verify, and update information:
- Lack of funding and training on evaluation methodology seriously impedes the quality of information and service;
 - Lack of training to guide the management of information may have a negative impact on the quality of information and its usability by consumers;
 - Lack of compatible hardware and software can impede the ability to transfer and share data from program to program;
 - Lack of a standard taxonomy and definition of terms can result in inconsistent information disseminated to consumers; and
 - Lack of standards for data collection, data verification, and updates can impede the quality of information.
5. Outreach efforts to target populations are ineffective and/or non-existent:
- Formal evaluation of the target population is sporadic or lacking in quantifiable measures of effectiveness;
 - The lack of available information on quality indicator measures. e.g., "consumer report" type rating for Assistive technology devices;
 - Lack of information on problem-solving strategies that allow consumers to maneuver through a complex system of care;
 - Underserved populations are not targeted or not reached due to a heavy reliance on traditional publicity and outreach methods;
 - Outreach efforts are primarily in written format, thereby limiting the target population; and
 - The lack of formal evaluation can result in services that do not meet the needs of the target audience.

RECOMMENDATIONS

In response to the major findings of the study, the following recommendations are made to NIDRR. The recommendations are grouped into four major areas: Policy & Coordination of AT I & R Services; Information Management; Staffing of AT I & R Services; Outreach; and Promoting AT I & R Services.

POLICY & CO-ORDINATION OF I & R SERVICES

1. Provide leadership to develop a National Assistive Technology Information and Program Referral Coordinating Institute. This initiative will provide the needed training and technical assistance support to regional, state and local

information programs. NIDRR will provide the oversight for the activities of the Coordinating Institute. This includes and is not limited to the following :

- Facilitate an orchestrated approach for the delivery of AT I & R services.
 - Provide technical support to AT I & R services as requested or needed. Develop a technical assistance manual for the coordination of AT I & R services, which details strategies within the context of the options available to deliver I & R services.
 - Develop national training materials to enhance the delivery of AT I & R services, and begin to address I & R quality standards
 - Provide training to enhance the capacity of I & R staff to deliver AT I & R services. Develop and implement a plan for a fully-coordinated AT I & R delivery system, with centralized functions providing technical support needed by community AT I & R services.
2. Develop a national classification schema or "taxonomy" for the delivery of AT I & R services, that integrates well with existing other services delivery taxonomies. Uniform terminology will greatly enhance smoother functioning of AT programs and services.
 3. Until such time, when state and local information programs have the capacity to be able to meet regional information needs, establish a national AT I & R toll-free telephone number that works in tandem with existing programs, to link persons with disabilities and AT services providers with appropriate resources at the national, state and regional levels. This service must be accessible in a variety of formats and provide linkages to referral at the local and state levels.
 4. Develop and implement initiatives that recognize the value of I & R services and build support for a coordinated system.
 5. Convene a national meeting of federal agencies to develop strategies designed to help coordinate and improve the delivery of I & R services. As a result of this meeting, identify a National Assistive Technology Information and Program Referral Task Force to develop strategies for improved inter-agency coordination of technology-related services. This task force should include representatives from consumer groups, professional associations, public-sector agencies, private non-profit agencies, private for-profit companies, and I & R practitioners. This initiative should examine ways to capitalize emphasis on use of computers and other similar technologies in other disciplines and agencies such as NASA, Office of Technology Transfer etc..
 6. Conduct field initiated research of I & R "best practices" and their application in the dissemination of AT information.
 7. Establish a national Assistive technology evaluation project to provide indicators to help consumers determine the quality and applicability of services and devices in meeting their technology needs.

8. Conduct a national awareness campaign on Assistive technology with parallel emphasis on I & R activities at the regional, state, and local levels. The target population of this campaign will be consumers of technology-related services, with emphasis on reaching both formal and informal resources utilized by persons with disabilities.

As we examined and analyzed various facets of I & R programs, we were able to observe a variety of effective methods to improve current I & R practices. These are summarized as recommendations and guidelines that may be implemented in stages, as resources become available. They are stated here to indicate their importance, and that they also play key roles in affecting effectiveness of the entire I & R process.

INFORMATION MANAGEMENT RECOMMENDATIONS

1. Establish a mechanism to review, modify, or adapt the "Standards for Information and Referral" and the "Taxonomy of Human Services", developed by the Alliance for Information and Referral Systems, for use by NIDRR-funded AT I & R services. If adaptation is not feasible, develop standards and an Assistive technology services taxonomy.
2. Provide the technical and training support for projects to implement minimum standards on information management and a taxonomy for the delivery of AT I & R services.
3. Establish annual priorities for field initiated research on the "best practices" in the delivery of AT I & R services.
4. Establish a mechanism to examine hardware and software options for all NIDRR-funded AT I & R services and determine their suitability, strengths, and weaknesses.
5. Develop guidelines and options for the selection of computer hardware and software to maximize compatibility among AT I & R services. The lack of compatibility can severely restrict the ability to electronically link AT I & R services.
6. Provide technical support to AT I & R services in the selection and utilization of computer hardware and software.
7. Develop consumer-responsive guidelines and evaluation strategies to measure the effectiveness of AT I & R services.

STAFFING AT I & R SERVICES RECOMMENDATIONS

1. Establish mechanisms to develop minimum competency guidelines for AT I & R staff.

2. Develop mechanisms to provide technical and training support for AT I & R services and I & R staff to implement the following:
 - Implementing standards;
 - Utilizing an AT I & R Services Taxonomy;
 - Meeting minimum competency levels; and
 - Developing in-depth expertise in various health and human service programs and technology-related issues.
3. Develop mechanisms for sharing training materials, innovative approaches, strategies, and technological applications.

OUTREACH RECOMMENDATIONS

1. Establish mechanisms to develop and implement minimum standards of evaluation on the effectiveness of AT I & R services.
2. Develop outreach partnerships with corporations, public and private organizations, broadcast media, civic associations, and other groups to launch a national awareness campaign on Assistive technology.
3. Establish demonstration projects to test innovative approaches to underserved and under-represented groups by AT I & R services.
4. Establish a mechanism to provide technical support and training on outreach strategies with formal and informal information brokers.
5. Provide the technical support and resources to AT I & R services for developing outreach strategies with underserved and under-represented groups.

PROMOTING AT I & R SERVICES RECOMMENDATIONS

1. Initiate local community promotional campaigns that parallel a national Assistive technology awareness campaign. Local community promotional campaigns can include public service announcements, video productions, and printed media.
2. Establish statewide 1-800 AT I & R telephone numbers wherever they do not exist. These state numbers are an essential link between the national 1-800 system and local communities.

All of our recommendations are base upon a statistically validated representative sample population. There are some stated limitations, however they are not statistically significant to make appreciable difference. Our research was very thorough and the approach used divided the research into five components for this study:

PHASE I:

Expert Panel Group: A group of 16 individuals from the field of AT I & R provided input into the overall design of the research, reviewed the findings, and contributed to the final recommendations of the study.

PHASE II:

Key Informant Survey: A total of 541 AT I & R providers assessed the current state-of-practice in the field through a survey. Additionally, this survey tool addressed the feasibility and desirability of establishing a national Assistive technology information and program referral network.

PHASE III:

Consumer Needs Perspective: Nationally, a total of 4,298 individuals determined the AT I & R needs of individuals with disabilities through a survey. Approximately 100 persons with disabilities of under-represented groups not found in the survey population provided their perspective via individual and group interviews.

PHASE IV:

Regional Focus Groups: Four focus groups examined the preliminary findings of the study developed in phases I through 3. These groups sought to clarify the initial findings and provided input on final recommendations. A total of 62 individuals participated in the focus groups.

PHASE V:

Technical Barriers: The researchers examined the technical barriers that might impede the establishment of a national AT I & R network.

STUDY PRODUCTS

- A comprehensive **Final Report** that integrates all phases of the research conducted in this study;
- An **Executive Summary** of the Final Report;
- A detailed **Feasibility Report** that explores impediments to development of a National AT I & R Network;
- A **Consumer Perspective Report** that examines the technology-related information needs of consumers;
- A **Directory of AT I & R Providers**; and
- An **Annotated Bibliography of AT I & R Related Publications**.

In conclusion, I wish to reiterate the sentiments of many who helped us with this research, that establishment of National Information and Program Network would be an essential catalyst to make other Assistive Technology programs more efficient and effective. Copies in alternative formats of all reports are available upon request from the Center for Developmental Disabilities at the University of South Carolina. We would be very happy to

provide any more clarification or entertain any inquiries about this research study. On behalf of the staff, I am very honored for this opportunity to provide this testimony to this distinguished group of people.

Submitted with Due respect to the Sub-Committee by

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**NATIONAL ASSISTIVE TECHNOLOGY INFORMATION &
PROGRAM REFERRAL FEASIBILITY AND
DESIRABILITY STUDY**

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LIST OF RECOMMENDATIONS

A NATIONAL AGENDA FOR IMPROVING AT I&R SERVICES

POLICY RECOMMENDATIONS

- Establish a national AT I&R network
- Commit federal resources to implement strategies to improve the state of AT I&R practice
- Commit resources to improve the delivery of AT I&R services
- Convene a national meeting of federal agencies
- Convene a National Assistive Technology Information and Program Referral Commission
- Establish a national AT I&R toll-free telephone number
- Establish a national assistive technology evaluation project
- Conduct field initiated research of I&R "best practices"
- Develop a national classification "taxonomy" for the delivery of AT I&R services
- Conduct a national awareness campaign on assistive technology
- Develop a national resource and technical support coordinating institute

COORDINATION OF AT I&R SERVICES RECOMMENDATIONS

- Implement coordination strategies between federal agencies providing I&R services
- Develop a technical assistance manual for the coordination of AT I&R services
- Provide leadership to develop a National Assistive Technology Information and Program Referral Coordinating Institute
- Develop and implement a plan for a coordinated AT I&R delivery system
- Develop and implement initiatives that recognize the value of I&R services

INFORMATION MANAGEMENT RECOMMENDATIONS

- Establish a mechanism to develop standards and an assistive technology services taxonomy
- Provide the technical and training support to implement minimum standards on information management
- Establish annual priorities for field initiated research on the "best AT I&R practices"
- Examine hardware and software options for all NIDRR-funded AT I&R services
- Develop guidelines and options for the selection of computer hardware and software
- Provide technical support to AT I&R services
- Develop consumer-responsive guidelines and evaluation strategies

STAFFING AT I&R SERVICES RECOMMENDATIONS

- Develop competency guidelines for AT I&R staff
- Develop mechanisms to provide technical and training support for AT I&R services and I&R staff
- Develop mechanisms for sharing training materials, innovative approaches, strategies, and technical applications

OUTREACH RECOMMENDATIONS

- Develop and implement minimum standards of evaluation
- Develop outreach partnerships
- Establish demonstration projects serving underserved and under-represented groups by AT I&R services
- Provide technical support and training on outreach strategies with formal and informal information brokers
- Provide the technical support and resources to AT I&R services

PROMOTING AT I&R SERVICES RECOMMENDATIONS

- Initiate local community promotional campaigns
- Establish statewide 1-800 AT I&R telephone numbers

Chairman OWENS. Thank you.

Mr. Mark Odum, National Rehabilitation Information Center, Silver Spring, Maryland.

Mr. ODUM. Thank you for giving me the opportunity to speak before the subcommittee. It is a privilege to be part of this process and an honor to provide testimony to be included as part of the deliberations regarding the reauthorization of the Technology Assistance for Individuals with Disabilities Act and, more specifically, make comments on the delivery of assistive technology information to the end users, persons with disabilities.

I just want to say a little bit about myself. At the age of 20, I incurred a spinal cord injury which drastically changed what I perceived my life would be. I was 2 years into college, and my physical life was pretty much stripped from me, somewhat lost.

Quickly after that, I was introduced to computers and home computers and realized this is a big avenue. It is an equalizer that, if used properly, could put me on a level playing field, and between my belief in this new technology of computers and my joy for helping people, I have kind of married these two and gone into providing information to people with disabilities, service providers, and professionals, to help other people with disabilities that have not been as fortunate as me.

Through that, I continue to work and enjoy all of the activities that I am able to do, including testifying here.

Shortly after I graduated from the University of Maryland, I was employed to work with the National Rehabilitation Information Center, which had just started out 15 years ago. I have been there all but 3 years, when I went to Georgetown University to do some work. So, I have a good feel for the delivery of rehabilitation and disability information over the past 15 years.

Let me just go into a little detail about NARIC's origin and where it is today, especially regarding its products and services.

The concept of a National Rehabilitation Information Center was first mentioned in the legislation during the 1960s and subsequently formalized in the Rehabilitation Act of 1973. But, it was not until 1976, when George Washington University performed a feasibility study outlining the need for a specialized collection of information and identifying specific components and tasks for such an operation, that a path was set for what was to become a premier source of national disability and rehabilitation information for professionals and consumers alike.

The basic premise of this feasibility study was that the Federal Government, specifically the Rehabilitation Services Administration and NIH, were spending large amounts of money for many worthy projects that had been generating a great deal of practical information, but this information had no formal mechanism for its dissemination.

Hence, many of these data were either lost or they just sat on the shelves or in the closets of their prospective project officers.

In reality, no matter how valuable the information might have been, it was not getting into the hands of those who needed it the most—consumers and service providers—and therefore rendered nearly worthless.

NARIC was extremely innovative from its beginning. Catholic University won the award and implemented the feasibility study recommendations to manage as much of the information contained in the center as possible by computerized methods.

As my friends in the library world like to say, it is one of the oldest collections never to be organized by a manual card system. What an advantage. Fifteen years later, the database structure is exactly the same and continues to be used in responding to almost 20,000 requests for information annually.

Shortly after NARIC was established, four significant additions were made to meet the growing need for specific rehabilitation and disability information. I mention these because they are consistent with the recommendations being made 10 years later through the feasibility study.

First, it was decided to expand the scope of the collection to include information not funded by the Federal Government, such as journal articles and books published by public and private enterprises.

Second, a highly-specialized collection of information on commercially-available devices and assistive equipment was added to the inventory of available information being disseminated by NARIC.

This database was initially collected and manually organized by an occupational therapist from the University of Tennessee, Marian Hall.

As a part of this enhancement of NARIC's realm, both NIHR and the State of California provided funds to computerize this collection of information and designed the basics of this database after the scheme set up to organize NARIC's primary database rehabilitation data. This database of product and device information was named ABLEDATA.

In 1987, NIDRR separated ABLEDATA tasks from the NARIC contract and, after a year of lying dormant, the ABLEDATA contract was awarded to Newington Children's Hospital.

In 1992, Macro International won the recompetete for ABLEDATA and joined its services with NARIC—Macro also administers the NARIC program at this time—thus making it easier for consumers and service providers to access complementary information.

The third change was to fund NARIC as a contract rather than a grant and hold its administering body accountable for successfully performing specific tasks to accomplish its dissemination and utilization mission.

The final modification during these years, the introduction of a toll-free 800 phone number, would change NARIC's course and set a theme which continues to grow under Macro's tutelage of both NARIC and ABLEDATA.

More and more, consumers are taking control of their lives, as we have heard here today, and seeking information for their personal use.

The medical model of having to go through a professional to get an interpretation or clarification of bewildering scientific jargon was becoming archaic, even unacceptable. No longer were health professionals serving as the middle person for the flow of information.

Almost overnight, statistics showed a major shift in NARIC's user base. Prior to the 800 number, persons with a disability and their family members were always one of the smallest categories of users. Since that time, monthly statistics continually show that nearly 40 percent of NARIC's users are consumers, including family and friends, by far the largest category of users.

Other groups of users include educators, administrators, students, therapists, librarians, and counselors.

In order to reach this audience, the NARIC project began to increase publishing efforts. These publications have grown exponentially through Macro's leadership over the years, to the point where NARIC and ABLEDATA projects now, in 1993, produce directories, thesauri, fact sheets, resource guides, a newsletter, bibliographies, and other assorted informational products.

Macro has made sure all the Center's publications are available on alternative media—large print, audio-cassette, braille, and electronically on diskette—and in Spanish.

One often unheralded publication of the Center is the NARIC thesaurus. In conjunction with development of the rehabilitation data database in 1979, a thesaurus was initiated to define and control the index terms or descriptors used to identify each document in the collection.

This thesaurus was designed after the Eric Thesaurus of Descriptors, which was recognized as a leader in the field at the time.

Over the years, the NARIC thesaurus has evolved along with the changes in vocabulary associated with the disability movement. Each change, addition, or deletion has been specifically reviewed and approved by a NIDRR project officer at the time.

In 1987, when Macro began to operate NARIC, a major change was made in the original focus to reconstruct the thesaurus to conform to the ANSI standards set for all thesauri. Scope notes were added to help clarify and further define each term. Additions such as broader terms, narrower terms, related terms were made where appropriate.

Again, terms have been added, changed, or deleted each year. However, I feel that the fourth edition of the thesaurus remains a standard within the highly-specialized language associated with the rehabilitation and disability field.

I have spoken about the information in publications maintained by NARIC. I want to spend some time reviewing what I refer to as the heart-and-soul of our information center, the information and referral system.

To address Girish's concern, yes, we are—I do not want to say we are overwhelmed. We could be nearly overwhelmed.

I have three librarians who answer those 20,000 requests a year, but we work very hard to automate that system, so that they can reach as much information from their desks, from a computer as possible and get as much support staff to pull the documents, photocopy them, deliver, invoicing, and all that.

So, what started out in 1987 as 300 requests a month with three information specialists now is a little bit under 2,000 requests a month. We do handle that, although I do not think we can fit too much more into that sack.

Chairman OWENS. Those librarians are amazing people, aren't they?

Mr. ODUM. Yes, very resourceful.

For the most part, the basics have remained the same over 15 years of NARIC's existence. Anyone can initiate an information request either by calling, voice, fax, or text telephone, writing, mail, E-mail, or other electronic means, or visiting the Center and speaking with an information specialist.

Our information specialists are trained and continue to receive ongoing training on a monthly basis to discern each individual's specific request through a highly-structured intake interview process.

Once the request has been determined and agreed upon, we see it as almost a covenant between the patron and the information specialist. A work order is prescribed and, depending on the nature of the request, action is taken by the information specialist exclusively or by a number of staff who will be involved in a process to satisfy the request and deliver the answer efficiently.

At this time, we have three librarians. They are very cognizant of the special situations. Two of them have disabilities. The third was raised by a parent with a disability. They are very masterful in fielding emotionally-charged requests that conventionally accompany hot-line calls, and they take pride in helping people. They often relate stories of how they got the right answer to a person who had nowhere else to turn.

Every week, we get thank-you notes from people or parents thanking us for making a difference in their lives. We often state that these letters are as good as paychecks.

As part of NARIC and ABLEDATA's effort to keep in communication with our patrons, we maintain an extensive mailing list which currently contains the names of more than 21,000 individuals and organizations. This mailing list is updated daily and continues to grow at a net rate of about 200 a month.

To maximize the various uses for the list, entries are coded into 70 categories according to status and function. The more popular categories include individuals with disabilities, rehabilitation facilities, organizations serving persons with disabilities, manufacturers and distributors of assistive technologies—and by the way, we have more than 4,500 of those in our directory, for the question that was asked earlier by Mr. Scott—and independent living centers.

Through this list, we are able to tailor special projects for specific target audiences. For example, currently we have more than 4,800 persons with a disability or a family member or friends on the list.

Given all these activities, one might think that NARIC and ABLEDATA is the end-all or be-all in the dissemination of rehabilitation and disability information. This is not the case.

For instance, NIDRR currently funds over two dozen projects in addition to the funded Assistive Technology Act States whose central focus is to generate and disseminate information about various aspects of assistive technology alone.

The number does not include the rehabilitation engineering centers or the small business innovative research projects and other projects whose main focus is the design or production of devices.

Some of these projects are funded under the Assistive Technology Act to conduct training or public awareness; others engineering centers whose focus is the improvement of assistive technology services in specific areas such as vocational rehabilitation, services to older persons, device evaluation, or technology transfer.

Still others are small projects that would address a narrower topic, such as the use of assistive technology by parents with disabilities.

Finally, several projects focus almost exclusively on information dissemination, such as ABLEDATA and the project conducted by Computers to Help People.

What all these projects have in common is a central focus of generating and disseminating information about assistive technology devices and services.

In addition to these projects, several projects whose primary focus lies elsewhere have disseminated valuable information on assistive technology.

For example, last year the Arkansas Research and Training Center in Vocational Rehabilitation produced an excellent monograph entitled "The Provision of Assistive Technology Services in Rehabilitation."

Three of the regional information exchanges funded by NIDRR include the provision of rehabilitation engineering services in the areas of exemplary practices which they work to identify and promote.

In fact, the trend requiring each project to become more accountable in their dissemination and utilization efforts has been made even more apparent with the new legislation written into the Re-authorization of the Rehabilitation Act.

The basic notion requiring NIDRR projects to include a dissemination component as part of their basic service will exponentially increase the number of contact points available for consumers and professionals.

Now, as you can see, there is a large number of ongoing efforts that are creating more usable information while at the same time providing some sort of a dissemination role with support from an information or referral effort.

Each has a particular domain. It sometimes intermixes with other collections or efforts, and it is here where strong, well-defined undertakings must have a specific set of tasks to organize and lead all of these ongoing endeavors into the next millennium.

This brings me to the specifics of the feasibility study authored by the Center on Developmental Disabilities.

First, I must congratulate the principles who undertook a project of such magnitude. To try and put one's fingers on the pulse and needs and desires of this Nation's disability and rehabilitation community, especially with diverse assistive technology information needs of consumers, is an enterprise of unbelievable proportions.

I would guess that, given pure numbers and variances with the information requests that I have witnessed over the 15 years, that a true picture of this population is nearly impossible.

I appreciate the design and the use of the surveys, both for consumers and service providers, but it is my feeling that in order to

get an accurate picture of this distinctive consumer population, thousands of completed surveys and interviews would be needed.

Given the hundreds of disabling conditions and the uniqueness within each of these conditions, there are literally millions of differences from consumer to consumer.

I feel that using the responses of 548 consumers to represent the needs and desires of millions of Americans with disabilities weakens the perspective of the consumer in the study.

This is not to say that the final recommendations do not have merit; they do. In fact, much of what has been recommended is already being done, according to my knowledge.

To strengthen the consumer's perspective on these issues, it would be necessary to gain more suggestions and comments. Because of the short amount of time made available to comment on the study and the lack of publicity regarding the opportunity to make comments, perhaps it would be possible to have other avenues made available for the public, especially consumers and service providers, to make comments and provide further expertise to the subcommittee.

The study does not give detail or depth in its assessment of what is currently being done in the field. I would like to have seen a more detailed report of existing programs and projects linking who is doing what in regard to each of the recommendations.

For example, I know the University of South Carolina Center for Developmental Disabilities staff works in close concert with a fairly new group, FIND—Forum for Information Networking in Disability—to move along with the notion of a standardized taxonomy scheme. Yet, the good work that they are doing is not brought into the study's sphere.

Under another recommendation, much of the work that is being encouraged under the 1-800 number system is currently being done by ABLEDATA as well as many of the more experienced Assistive Technology Act States. As more States are funded and previously-funded projects mature, even more of this work will be addressed.

The RESNA technical assistance projects provide training and identify exemplary projects and programs at its annual all-States conference, maybe not exactly what is being recommended, but they do have the network and they do have a great deal of experience with training these information and service providers.

What I am trying to say is that this study and its recommendations could be much stronger if it identified what is currently being done in the field and provided a plan with specific tasks to build upon what is currently being done rather than making recommendations for new efforts.

Not everything that has been recommended is redundant. In fact, probably the most compelling need is for a coordinating institute to bring specific standards for all general areas of operation with special considerations made for each unique category of providers and end users regarding the provision of rehabilitation and disability information management.

However, we must be careful not to create a monolithic center with no room for individuality where a big-brother sort of mentality exists. Remember, the challenge here is to bring everything together, not make everything look exactly alike.

A single resource coordinator working in a support group organization's library could never run their operation the same way or with the same standards that would be expected of a \$300,000-a-year national information dissemination and utilization project. Yet, they both provide services that are essential to their respective target audiences.

Probably the most needed recommendation is the concept of a national public awareness campaign. However, rather than establishing a grant project to advertise other projects' work, we should eliminate the middleman and allocate these funds to existing projects.

Very few Federal dollars are appropriated for public awareness and marketing efforts. In some ways, the current situation is akin to the earlier circumstance where useful information was being produced but nobody knew about it.

Now we have taken the concept a step further. We are doing a good job of collecting and organizing such essential information. However, we are falling short in our efforts to illuminate where these dissemination points are located and how to access the information.

If we do not begin to put more resources into promoting these existing programs, all that will have been accomplished is to have moved this information from the project officers' closets to the libraries. We have still not reached the end users.

I was talking with people about this, and one of the things that had come up was that there is a number of very excellent recommendations but they felt that there might be a little fluff; one of the places of fluff would be this one, in that it probably could not be funded. I really encourage a strong look at identifying these dissemination points.

I know, for instance, at NARIC, which operates under an \$800,000-a-year budget, I have trouble justifying ever even going across the Mississippi to a national conference or meeting, because it is just too expensive.

I cannot go to New Jersey, where I am going to reach 4,000 consumers, because it costs \$1,700 to have a booth.

So, even with a budget that big, most of those resources go into answering requests and providing publications. It does not get us out into the public.

I cannot buy advertising in these programs. What I do is barter my mailing list and say, "Here, you can have \$500 worth of mailing labels if you give me \$500 worth of advertising." It is a creative way to get the word out, but it is very inefficient. I strongly suggest looking closely at that recommendation.

I also feel that all of these recommendations should be structured as tightly as possible, more in the form of a contract rather than a grant. Under a contract, the exact tasks can be identified so that they are measurable, contain specific timelines, and distinguish precise resources to be used in the accomplishment of their goals and objectives.

In talking with a professional about the study, the concern regarding objectivity was raised. My response was that I felt this was very objective but that I could not say for sure because I did not

have enough information regarding the specific methods used in identifying this population.

Although it is too late in this instance, I do know a way to assure objectivity and suggest to this subcommittee that other recommendations in the future disqualify any of the feasibility authors or principles from receiving subsequent funding at least for the next 2 or 3 years.

In summary, I feel that the basic theme of this study to bring together all the information and dissemination efforts in order to provide better services and to continue to improve the quality of life for each of the millions of Americans must be advanced.

I am committed to continuing my personal pursuit of helping people with disabilities and would like to see this work encouraged with careful planning and controls to prevent expending unnecessary dollars on duplicate efforts.

Again, I thank the members of this subcommittee for the opportunity to provide my personal commentary and emphasize my willingness and heightened interest in being involved with this significant endeavor.

I also want to state, as a project director for NARIC, that our support and assistance to further the mission of the committee is available. We want to be helpful in any way and invite you to use all the resources housed at NARIC and ABLEDATA.

Thank you.

[The prepared statement of Mark Odum follows.]

STATEMENT OF MARK X. ODUM, PROJECT DIRECTOR, NATIONAL REHABILITATION
INFORMATION CENTER

Thank you for giving me the opportunity to speak before this subcommittee. It is a privilege to be a part of this process and an honor to provide testimony to be included as part of your deliberations regarding the reauthorization of the Technology Assistance for Individuals with Disabilities Act.

As an individual having incurred a spinal cord injury nearly 20 years ago due to a sporting accident, I have seen and been a part of great changes in the ways that persons with disabilities have been treated as well as how we have perceived ourselves. Through my personal experiences, I also know what a difference accurate, timely information—whether it is program information on a specific service, or product information regarding the latest technology available—can make in the daily life of a person with a disability. After my accident I returned to my undergraduate studies with a new focus—to help empower persons with a disability to gain the fullest quality of life, disability notwithstanding.

In June 1978, a time when the Rehabilitation Act of 1973 was beginning to effect changes, I became involved in the political transformations dictated by law as well as the social changes being afforded to an up-and-coming minority. I successfully sought election to the student government and helped set new policies in order to conform to the new regulations. I was primarily responsible for establishing one of the first disabled student service offices at an institute of higher education in the country. Through these ventures, I recognized a great feeling of enjoyment out of helping others less fortunate than I, and in a way, felt that through these efforts I was paying back all the people who had helped me.

Shortly after returning to school, I was introduced to the world of personal computers. Immediately I realized the potential of these "miracle" machines and recognized that this new technology was a great equalizer. With the help of my family, I acquired a personal computer for my home. What a godsend! It was as if a genie had been released from its lamp. To say that I embraced this technology would be an understatement. I could handle huge amounts of electronic data, regardless of the limitations due to my disability with ease. I was on a level playing field with my fellow students who could easily manage large volumes of books or documents that were otherwise physically inaccessible to me.

These two small but poignant revelations were major catalysts in elevating me to my present position as Director of the National Rehabilitation Information Center [NARIC].

In 1978 I was hired by The Catholic University of America [CUA] to work as a Program Specialist for the NARIC project. At that time NARIC was in its second month of funding as a dissemination and utilization grant by NIDRR's predecessor, the National Institute of Handicapped Research [NIHR]. Over the past 15 years I was involved with every aspect of this effort to collect, organize, and disseminate useful information regarding all aspects of rehabilitation and disability on a national level. Although I did leave the NARIC project for almost three years [December 1984 to October 1987], in many ways I am the institutional memory of this innovative project. To complete the circle, I returned to NARIC as the Media and Acquisitions Manager in 1987 when Macro International Inc. was awarded the contract to operate NARIC. Macro International is a 27-year-old for-profit company that offers a wide range of services including survey and market research, management consulting, training, and information systems. About 80 percent of Macro's work is for Federal agencies, with a strong emphasis in areas such as alcohol, tobacco, and other drug abuse prevention training; educational products development; disability and rehabilitation information management; and youth health risk surveys.

In 1990 I was appointed NARIC Project Director when my predecessor went to another project.

Let me go into some detail about NARIC's origin and where it is today, especially regarding its many products and services. The concept of a national rehabilitation information center was first mentioned in legislation during the middle 1960s and subsequently formalized in the Rehabilitation Act of 1973. But it wasn't until 1976, when The George Washington University performed a feasibility study outlining the need for a specialized collection of information and identifying specific components and tasks for such an operation, that the path was set for what was to become a premier source of national disability and rehabilitation information for professionals and consumers, alike. The basic premise of this feasibility study was that the Federal Government, specifically Rehabilitation Services Administration [RSA] and NIHR, was spending large amounts of money for many worthy projects that had been generating a great deal of practical information, but this information had no formal mechanism for its dissemination. Hence, many of these data were either lost or they just sat on the shelves or in the closets of the respective project officers. In reality, no matter how valuable the information might have been, it was not getting into the hands of those who needed it the most—consumers and service providers—and therefore, rendered nearly worthless.

In 1978 CUA's School of Library and Information Science won the award to begin such an undertaking.

NARIC was extremely innovative from its beginning. CUA implemented the feasibility study's recommendations to manage as much of the information contained in the Center as possible by computerized methods. As my friends in the library world like to say, it is one of the oldest collections never to be organized by a manual card system. What an advantage! Fifteen years later the database structure is exactly the same and continues to be used in responding to almost 20,000 requests for information annually.

In its first two years of funding, NARIC collected and organized RSA- and NIHR-funded information almost exclusively. Although most of this original collection was geared toward and used primarily by service providers and rehabilitation professionals, NARIC's popularity grew to the point where having information to assist professionals with their research was not enough. Within the next three years, four significant additions were made to the project in order to meet both the growing amount of, and the growing need for, specific information.

First, it was decided to expand the scope of the collection to include information not funded by the Federal Government such as journal articles and books published by private enterprises. Second, a highly-specialized collection of information on commercially-available devices and assistive equipment was added to the inventory of available information being disseminated by NARIC. This database was initially collected and manually organized by an occupational therapist from the University of Tennessee—Marian Hall. As a part of this enhancement of NARIC's realm, both NIHR and the State of California provided funds to computerize this unique collection of information and designed the basics of the database after the scheme set up to organize NARIC's primary database—REHABDATA. This database of product and device information was named—ABLEDATA. [In 1987, NIDRR separated ABLEDATA tasks from the NARIC contract. After a year of lying dormant, the ABLEDATA contract was awarded to Newington Children's Hospital. In 1992, Macro

International won the recontract for the ABLEDATA project and joined its services with NARIC where possible, thus making it easier for consumers and service providers to access complementary information.] The third change was to fund NARIC as a contract rather than a grant and hold its administering body accountable for successfully performing specific tasks to accomplish its dissemination and utilization mission. The final major modification during these years—the introduction of a toll-free 800 phone number—would change NARIC's course and set a theme which continues to grow under Macro tutelage of both NARIC and ABLEDATA.

More and more, consumers are taking control of their lives and seeking specific information for their personal use. The medical model of having to go through a professional to get an interpretation or clarification of bewildering scientific jargon was becoming archaic, even unacceptable. No longer were health professionals serving as the middle person for the flow of information. Almost overnight, statistics showed a major shift in NARIC's user base. Prior to the 800 number, persons with a disability and their family members were always one of the smaller categories of users. Since that time, monthly statistics continually show that nearly 40 percent of NARIC's users are consumers, including their family and friends—by far, the largest category of users. Other groups of users include educators, administrators, students, therapists, librarians, and counselors.

In order to reach this burgeoning audience, the NARIC project began to increase its publishing efforts. Besides initiating its trade newsletter in 1980, *The Pathfinder*, NARIC was charged with publishing more patient education-type literature such as resource guides. The research community was not forgotten or overlooked in these efforts and annotated bibliographies on specific research topics as well as literature reviews were produced too. At the same time ABLEDATA-related information was being condensed and rewritten in easily understandable layperson's terms and published as fact sheets, each with a specific genre of products or devices in mind. Where possible, evaluation information was included; however, very little of this type of information was being generated by qualified professionals. Macro built on these efforts and began to print short, informative one-page responses to frequently asked questions. These publication efforts have grown exponentially through Macro's leadership over the years to the point where the NARIC and ABLEDATA projects now, in 1993, produce directories, thesauri, [one for each of the two major databases], fact sheets, resource guides, a newsletter, bibliographies, and other assorted informational products. Macro has made sure that all of the Center's publications are available in alternative media—large print, audiocassette, braille, and electronically on diskette—and in Spanish.

As part of Macro's commitment to provide useful information and to be responsive to the information needs of NARIC's and ABLEDATA's constituency, some products have been assembled outside of the contract's requirements. One such example is the *Directory of Librarians and Information Specialists in Disability and Rehabilitation*. There has always been a need to identify individuals who are experts within any specific category or field. To help answer this need, Macro sent out press releases and order forms to editors of disability and rehabilitation publications, librarians, independent living centers, support groups, and advocacy organizations on the NARIC mailing list at no cost to the project. We asked that anyone who felt they had some expertise to share [on any of the more than 300 subject areas within rehabilitation or disability disciplines] and would be willing to receive phone calls, to complete the directory form and return it to NARIC. Within eight weeks we had more than 400 responses. When the directory was published, we announced that the directory was simply a list of self-described experts willing to share their specific knowledge for free. Over the past four years, hundreds of directories have been disseminated and efforts to update the first edition of the directory are currently underway.

Other directories produced by the NARIC and ABLEDATA projects include the *NIDRR Program Directory*, *NARIC Guide to Disability and Rehabilitation Periodicals*, *Manufacturer's Telephone Directory*, and *A Directory of National Information Sources on Disability*. In addition to these directories we produce 16 ABLEDATA Fact Sheets [each sheet describes a specific group of devices with the only exception being a notable one: *Fact Sheet on Funding Assistive Technologies*], three NARIC Resource Guides and a newsletter—*NARIC Quarterly: A Newsletter of Disability and Rehabilitation Research and Resources*.

One often unheralded publication of the Center is the NARIC thesaurus. In conjunction with the development of the REHABDATA data database in 1979, a thesaurus was initiated to define and control the index terms or descriptors used to identify each document in the collection. This thesaurus was designed after the *ERIC Thesaurus of Descriptors* which was recognized as the leader in the field at

the time. Over the years the NARIC thesaurus has evolved along with the changes in vocabulary associated with the disability movement. Each change, addition, or deletion has been specifically reviewed and approved by the NIDRR Project Officer at the time. In 1987, when Macro International began to operate NARIC, a major change was made in the original focus to reconstruct the thesaurus to conform to the ANSI standards set for all thesauri. Scope notes were added to help clarify and further define each term, and additions such as broader terms, narrower terms, related terms, and antonyms were made where appropriate. Again, terms have been added, changed, or deleted each year, however, I feel that this fourth edition of the thesaurus remains a standard within the highly-specialized language associated with the rehabilitation and disability field.

Now combined with NARIC's thesaurus in a uniquely bound, joint publication of the NARIC and ABLEDATA projects, is the *ABLEDATA Thesaurus*. This document constitutes the controlled vocabulary used to identify product and design entries in the ABLEDATA database of assistive technology and rehabilitation equipment. There are currently 17 major sections of the thesaurus. Each section is divided into subheadings of major groupings within the section, and each subheading is again divided into identifiers [sub-subheadings], which loosely correspond to the *broader terms* of the NARIC thesaurus. The lowest level of the outline is the generic term. All of the levels of the *ABLEDATA Thesaurus* serve to assist in searching the database, and give a logically ordered, alphabetical reference detailing the scope and extent of the database records. New generic terms and identifiers are added as needed, with the approval of the NIDRR Project Officer. To date, 36 generic terms have been added since Macro began administering the project in February 1992. When possible, new generic terms are worded with the same terminology as found in the Americans with Disabilities Act Accessibility Guidelines [ADAAG] and other current documents pertaining to the field of assistive technology to maintain a standardized vocabulary. Many information centers and specialty databases consider the *ABLEDATA Thesaurus* the accepted dictionary for assistive technology, rehabilitation, therapeutic and home health care products.

I have spoken about the major databases and publications maintained by NARIC. Now I want to spend some time reviewing what I refer to as the heart-and-soul of our information center, the information and referral system. For the most part, the basics have remained the same over the 15 years of NARIC's existence. Anyone can initiate an information request by either calling [voice, fax, or text telephone], writing [mail, E-mail, or other electronic means], or visiting the Center and speaking with an information specialist. Our information specialists are trained [and continue to receive ongoing training on a monthly basis] to discern each individual's specific request through a highly-structured intake interview process. Once the request has been determined and agreed upon [we see it as a covenant between the patron and information specialist], a work order is prescribed and depending on the nature of the request, action is taken by the information specialist exclusively, or a number of staff will be involved in the process to satisfy the request and deliver the answer efficiently.

At this time we have three full-time information specialists; two have their MLS degrees in library and information science [the third is a few credits short of her MLS degree]. Two are persons with a disability and the third was raised by a parent with a disability. They are very cognizant of the special situations routinely a part of many requests and masterful in fielding emotionally-charged requests that conventionally accompany "hotline" calls that come into the Center through the toll-free phone line. Each information specialist takes pride in helping people and they often relate stories of how they got the right answer for a person who had nowhere else to turn. Every week we get thank-you notes from all levels of individuals, whether they are the head of an agency or a parent of a child with a disability, thanking us [or the individual information specialist] for making a difference in their lives. Those letters are as good as a paycheck when it comes to the personal gratification one gets for a job done well.

One of the more amazing accomplishments within our information and referral efforts over the past five years has been our ability to successfully answer a growing number of requests. When Macro began operating NARIC in early 1988 we were answering approximately 300 requests for information a month. Over the last six months we have successfully answered an average of almost 2,000 requests for information each month with three information specialists and the assistance of two support staff. We have met this challenge with a two-pronged strategy revolving around the principles of being as efficient as possible. First, we have made all information [except for the ephemeral literature] available to the information specialists electronically. Through the Center's computer system, an information specialist [or any

staff for that matter] can access information from any of the Center's eight databases, update or initiate the patron's record of basic demographic information, and initiate a work order for a support staff to complete [along with an automated invoicing system that calculates all charges, including postage charges, and automatically updates our mailing list information]—all without leaving their work area. Of course, not all requests are as easy as this, but many can be answered quickly. Secondly, we utilize support staff and volunteers wherever possible to provide assistance with pulling documents from the shelves, photocopying, packaging the request once it has been approved by the information specialist originating the request, and finally, reshelving any materials used to answer the request.

As part of NARIC's and ABLEDATA's effort to keep in communication with our patrons, we maintain an extensive mailing list which currently contains the names of more than 21,000 individuals and organizations. This mailing list is updated daily and continues to grow at a net rate of approximately 200 every month. To maximize the various uses for the mailing list, entries are coded into 70 categories according to status and function. The more popular categories include individuals with disabilities, rehabilitation facilities, organizations serving persons with disabilities, manufacturers and distributors of assistive technology, and independent living centers. Through this list we are able to tailor special projects for specific target audiences. For example currently we have more than 4,800 persons with a disability or a family member or friend in the list.

Given all these activities, one might think that NARIC and ABLEDATA is the end-all or be-all in the dissemination of rehabilitation and disability information. This is not the case. For instance, NIDRR currently funds over two dozen projects *in addition to the funded Assistive Technology Act States* whose central focus is to generate and disseminate information about various aspects of assistive technology, alone. This number does *not* include Rehabilitation Engineering Centers [REC], Small Business Innovative Research [SBIR] projects, and other projects whose main focus is the design or production of devices. Some of these projects are funded under the Assistive Technology Act to conduct training or public awareness activities. Others are RECs whose focus is the improvement of assistive technology services in specific areas such as vocational rehabilitation, services to older persons, device evaluation, or technology transfer. Still others are smaller projects which address a narrower topic, such as the use of assistive technology by parents with disabilities. Finally, several projects focus almost exclusively on information dissemination, such as ABLEDATA and the project conducted by Computers to Help People. What all these projects have in common is a central focus of generating and disseminating information about assistive technology devices and services.

In addition to these projects, several projects whose primary focus lies elsewhere have disseminated valuable information on assistive technology. For example, last year the Arkansas Research and Training Center in Vocational Rehabilitation produced an excellent monograph entitled "The Provision of Assistive Technology Services in Rehabilitation." Three of the Regional Information Exchanges include the provision of rehabilitation engineering services in the areas of exemplary practices which they work to identify and promote.

In fact, the trend requiring each project to become more accountable in their dissemination and utilization efforts has been made even more apparent with the new legislation written into the Reauthorization of the Rehabilitation Act of 1973. The basic notion requiring NIDRR projects to include a dissemination component as part of their basic service will exponentially increase the number of contact points available for consumers and professionals.

For instance, the Trace Center which is located in the Waisman Center for Research on Developmental Disabilities at the University of Wisconsin-Madison, provides a wide range of information services to assist them with their activities and provide an avenue to disseminate their results. The Trace Center was started over 20 years ago to address the communications needs of non-vocal children and adults. Currently, the Trace Center's scope covers four principal areas: [1] communication, [2] control mechanisms to operate sophisticated assistive technologies, [3] computer access for persons with a disability, and [4] information system access.

Under these focus areas there are seven principal activities [1] basic research which fosters the design of devices and software, [2] the research and development of specific products [e.g., HyperABLEDATA which has a special interface to increase access to the ABLEDATA database; the Cooperative Service Directory Database which collects and disseminates product and service information on a local level; the Trace Voice Sampler that contains voice samples from major types of synthesizers; the Trace ResourceBook which has information on most of the assistive technology products for communication, control, and computer access; Design Guidelines for

Computers which can assist computer manufacturers in the design of more accessible computers; and a Campus/Library Information Systems Accessibility Manual which can be used for implementing computer accessibility in postsecondary education environments], [3] standards for the design and manufacturer of products to ensure compatibility, [4] commercial facilitation that assists with evaluating technological concepts and moving them into the marketplace, [5] information management which includes collecting and disseminating information on technology for communication, control, and computer access which includes information and referral work, as well as developing and improving access to other databases in the field of assistive and rehabilitation technology—especially making databases more accessible to consumers and service providers, [6] a training component as part of a workshop series, and [7] clinical services. Basically, the Trace Center's major focus is to create a more accessible world, especially within the electronic media.

As you can see, there is a large number of ongoing efforts that are creating more usable information while at the same time providing some sort of a dissemination role with support from an information and referral effort. Each has a particular domain that sometimes intermixes with other collections or efforts, and it is here where strong, well-defined undertakings must have a specific set of tasks to organize and lead all of these ongoing endeavors into the next millennium.

This brings me to the specifics of the feasibility study authored by the Center on Developmental Disabilities out of the University of South Carolina.

First, I must congratulate the principles who undertook a project of such magnitude. To try and put one's finger on the pulse of the needs and desires of this Nation's disability and rehabilitation community, especially the diverse assistive technology information needs of consumers, is an enterprise of unbelievable proportions. I would guess that, given pure numbers and variances within the information requests that I have witnessed over the past 15 years, that a true picture of the population cannot be done. I appreciate the design and use of the surveys—both for the consumers and the service providers—but, it is my feeling that, in order to get an accurate picture of this distinctive consumer population, thousands of completed surveys and interviews would be needed. Given the hundreds of disabling conditions and the uniqueness within each of these conditions, there are literally millions of differences from consumer to consumer [e.g., it is generally accepted that no two spinal cord injuries, except for complete transverse separations at the exact same level of the spinal cord, are identical and therefore, the abilities and needs of each of these 500,000 individuals are different]. I feel that by using the responses of 548 consumers to represent the needs and desires of 43 million Americans with disabilities weakens the perspective of the consumer in this study. This is not to say that the final recommendations do not have any merit. They do! In fact, much of what has been recommended is already being done, according to my knowledge.

To strengthen the consumer's perspective on these issues, it would be necessary to gain more suggestions and comments. Because of the short amount of time made available to comment on this study and the lack of publicity regarding the opportunity to make comments, perhaps it would be possible to have other avenues made available for the public, especially consumers and service providers, to make comments and provide further expertise to this subcommittee.

This study does not give very much detail or depth in its assessment of what is currently being done in the field. Certainly a comprehensive review of the current literature should be longer than four pages. I would like to have seen a more detailed report of existing programs and projects, linking who is doing what in regard to each of the recommendations. For example, I know that the University of South Carolina's Center for Developmental Disabilities staff works in close concert with a fairly new group—FIND [Forum for Information Networking in Disability] to move along with the notion of a standardized taxonomy scheme, yet the good work that they are doing is not brought into this study's sphere. Do we really need \$200,000 to bring together the top four or five thesaurus producers to agree upon specific definitions and promote this vocabulary when there are groups who have been working with this issue for years?

Under another recommendation, much of the work that is being encouraged under the 1-800 number system is currently being done by ABLEDATA as well as many of the more experienced Assistive Technology Act State projects. As more States are funded and previously-funded projects mature, even more of this work will be addressed.

The RESNA technical assistance project provides training and identifies exemplary projects and programs at its annual All States conference. Maybe not exactly what is being recommended, but they do have the network and they do have a great deal of experience with training these information service providers.

What I am trying to say is that this study and its recommendations could be much stronger if it identified what is currently being done in the field and provided a plan, with specific tasks, to build upon what is currently being done rather than making recommendations for new efforts.

Not everything that has been recommended is redundant. In fact, probably the most compelling need is for a coordinating institute to bring specific [including provisions that respect the unique desires and needs of the end users] for all general areas of operation, with special considerations made for each unique category of providers and end users, regarding the provision of rehabilitation and disability information management. However, we must be careful not to create a monolithic center with no room for individuality where a big-brother sort of mentality exists. Remember the challenge here is to bring everything together, not make everything look exactly alike. A single resource coordinator working in a support group organization's library could never run their operation or conform to the same standards expected of a \$300,000-a-year national information dissemination and utilization project. Yet, both provide essential services for their respective target audiences.

Probably the most needed recommendation is the concept of a national public awareness campaign. However, rather than establishing a grant project to advertise other projects' work, eliminate the middleman and allocate these funds to existing projects. Very few Federal dollars are appropriated for public awareness and marketing efforts. In some ways, this current situation is akin to the earlier circumstance where useful information was being produced but nobody knew about it. Now, we have taken this concept one step further. We are doing a good job of collecting and organizing such essential information for dissemination, however, we are falling short in our efforts to illuminate where these dissemination points are located and how to access the information. If we do not begin to put more resources into promoting these existing programs, all that will have been accomplished is to have moved this information from the project officers' closets to the libraries, but we still have not reached the end users. Professionals and consumers alike, still have to search for existing sources of information.

I also feel that each of the recommendations should be structured as tightly as possible, more in the form of a contract rather than a grant. Under a contract, exact tasks can be identified so that they are measurable, contain specific timelines, and distinguish precise resources to be used to accomplish the goals and objectives.

In talking with another professional about this study, the concern regarding objectivity was raised. My response was that I felt it was objective but that I couldn't say for sure because there was not enough information given regarding the specific methods used when identifying the sample populations. Although it is too late in this instance, I do know one way to insure objectivity—disqualify any of the feasibility authors or principles from receiving subsequent funding, at least for the next two or three years. Perhaps this is something that should be done for all studies of this type, routinely.

In summary, I feel that the basic theme of this study to bring together all of the dissemination and utilization efforts in order to provide better services and continue to improve the quality of life for each of the 43 million Americans must be advanced. I am committed to continue my personal pursuit of helping people with disabilities and would like to see this work encouraged with careful planning and controls as not to expend unnecessary dollars on duplicate efforts. Again, I thank the members of this subcommittee for the opportunity to provide my personal commentary and emphasize my willingness and heightened interest in being involved with this significant endeavor. I also want to state that, as Project Director of NARIC, I want to offer Macro's support and assistance to further the mission of this subcommittee. We want to be helpful in any way and invite you to use all of the resources housed at NARIC and ABLEDATA.

Chairman OWENS. Thank you, Mr. Odum.

In case you did not understand my remark about the librarians, it was self-serving. I am a librarian and wanted to make certain the record showed the contribution they are making.

Before we go on to the questions, I want to recognize Commissioner Susan Urofsky of the Department of Rehabilitative Services here in Virginia. She is one of our hosts, and we would like to thank her for hosting us today.

I also would like to point out that, in the back, we have some assistance technology devices on display. You are invited to take a look at those at the end of the hearing.

We also have some components of the Virginia Information Referral system back there, too. I hope you will have a look at that.

I yield to Mr. Scott for questions.

Mr. SCOTT. Mr. Chairman, you had put on the record that you are a librarian. I would like to—in light of some of the other comments made about funding, I want to point out that the distinguished Chairman of this subcommittee is also from New York, which may explain some of the comments on funding.

Mr. ODUM, I think you mentioned that after the 800 number had been instituted, the percentage of calls from consumers went up dramatically.

Mr. ODUM. That is correct.

Mr. SCOTT. Do you attribute all of that to the 800 number?

Mr. ODUM. I think it eased the way to access this information. If you are out in Ames, Iowa, and you need some information, it is awful easy to pick up a phone and have a free lifeline, if you will, to this National Center.

You do not know what this National Center is. You hear that you can get rehabilitation information, and you call up; whereas before, if you were to try and access us, it would have cost you the toll for that phone or you would have had to write some sort of a letter to get to us, and it was just very inefficient.

We want instantaneous gratification out of our actions. We would rather pick up a phone and hear something right away. We do not seem to, unless in most desperate times, write or take longer methods to try and get these sort of calls.

So, I do believe what it did was open up a real large conduit to the most desperate people out there that had no easier way to get information.

Mr. SCOTT. So, you are saying that most of the increase has come through the 800 number?

Mr. ODUM. No. Again, as I—80 percent of our information requests come through the telephones. We do not have it detailed to know how many are 800 as opposed to those that might call our regular lines.

We do have it geographically. So, I could probably go back and, assuming that most of the people calling out of our calling area are using the 800 number, I could then establish a number for that, but I would daresay most of them do come through the 800 number.

Mr. YAJNIK. Mr. Scott, may I make a comment?

Mr. SCOTT. Yes.

Mr. YAJNIK. An 800 line also provides a certain degree of anonymity to the people. Additionally, they are talking to somebody who can relate to them.

Many times—and I am sure Mark will attest to this—the people who are calling, nine times out of 10, do not know what questions to ask. It is the people that they talk to who are trained, who can be empathetic, who prompt them and are able to extract what the needs might be and what the other resources could be. That is a very important aspect of any information system.

It is very important because you can provide literature and you can mail things back to them and leave it for them to browse through and understand to their ability.

So, information specialists or people who are at the other end of the phone, provide a very important function that the 800 number provides. That's probably why a lot of the people—the increase could be attributed to that.

Mr. Scott. Mr. Odum, you mentioned you have three people responding; that you have developed what sounded like an individualized and customized response to each individual. You are doing about 100 a day. I guess my question is what kind of quality response can you give with that kind of volume?

Mr. Odum. I think we can give very good quality.

First off, you have to remember, it is the acquisition of the data collection where this process starts. If you are collecting good data, your chances of getting it out are that much better.

It is very important, in the intake interview, to ask specific questions of what this person needs. Through the telephone line, especially the 800 number, as Gary says, you can have this give-and-take, as we'll call it, an intake interview: What are you looking for? Okay. My son has such-and-such. How old is your son? It makes a difference if they are 12 or if they are 35.

So, through this give-and-take, what it comes down to is narrowing that information request, making sure that the information specialist has the correct request, restating it to that person, and then going to the collection, through the computerized needs or whatever, to try and discern this information.

If it is not available, then it is going to the next source or referral and trying to refer to the RESNA TA or to the local States who might have better local information.

Again, we are a national center. We do not have our hands on all the highly-detailed local information that is available out there, but hopefully we do know where to point the people out.

So, every request that we answer has a user services survey to go with it so that they can fill out and let us know how well we have done.

Mr. Scott. Can people actually get through on the phone?

Mr. Odum. Sometimes we hear that it is quicker to walk than to use that number. The phone is always busy, but the numbers are there.

Mr. Scott. Mr. Tremblay, on the loan program, we heard a 25-percent default rate, and your default rate is in the 1 percent, ½ percent range, depending on what number you are using.

Can we expect that kind of default rate—I guess we could expect that kind of default rate if we are judging people on creditworthiness.

What would happen to the people who, quite frankly, are not worthy of credit, and I say that because a lot of people in this situation, as the first witness testified, have expended themselves into bankruptcy because of the disabilities.

Does your program anticipate any extension of credit to those that may not be creditworthy?

Mr. TREMBLAY. Yes. Let me clarify one point. One out of every five applicants who comes into the program has no record of credit, and yet, their record of receiving a loan is close to over 95 percent.

When we talk about creditworthiness in the Maine loan program, I should have clarified that we are talking about a very liberal definition.

The reason that we created the loan program in the first place was because the conventional lending arena would not loan money for a lot of the technology, but beyond that it would not loan money to people or to a lot of the people with disabilities who needed technology, because they are on fixed incomes.

So, I should point out first that the Maine loan program experiences this default rate at the same time that it makes money available to a significant number of loan applicants that are on SSI and limited income.

Now, in some cases, those people need to have somebody co-sign, but in many cases we will collateralize that loan with the equipment.

For example, if a person needs money for, say, an automatic door opener that may cost \$750 to \$800 for their apartment that they can get into—or because they want to get into and out of it independently—we can set up a financing structure over 3 or 4 years, even with their limited income, so that they can afford one of these.

Mr. SCOTT. You had mentioned an average loan of about \$9,000, something like that. What portion of your loans go to individuals and what portion to commercial establishments?

Mr. TREMBLAY. The vast majority go to individuals. I think, out of the whole portfolio loaned to date of \$2.4 million, there is probably less than \$100,000 to commercial businesses, although we are seeing now an increase in applications from businesses because of the advent of the Americans with Disabilities Act and some of those requirements.

So, I think we can anticipate that more money in the future will be going to businesses. However, the legislation will only allow up to a maximum of 20 percent of the funds for businesses; fully 80 percent have to remain with individuals.

We heard in testimony, and I mentioned in my remarks, that when reasonable accommodations are made by businesses for persons with disabilities to come to work, 80 percent of those accommodations can be made with expenditures under \$500.

Some, obviously, will be much more than that, and having a loan fund will make it a lot easier on those businesses to comply.

Mr. SCOTT. Mr. Fifield, in training, should we have some kind of certifications or should grants have mandatory training components in them? It is one thing to say you ought to have training, but there ought to be some oversight. What is good training and what is bad training?

You want to make sure the information gets across, so is there any—do you have any idea what ought to be in the Act to make sure that we get good quality in terms of training, either certification or some kind of mandates?

Mr. FIFIELD. In our country, we usually leave that up to the States. States are responsible for certification in almost all cases

and licensing and so forth. They usually are working in conjunction with professional organizations that set some kind of standards, some types of—the level of competencies and so forth.

Those can be used very effectively, and I think that, rather than having to put that language into Federal legislation, the easiest way would be to include it as the State competencies or indicate that they have to establish those competencies.

I do know that several of the professional organizations are working very actively now to get competencies laid out in the area of assistive technology, so there is some level of standards or competencies which people can be held to.

Mr. SCOTT. Thank you, Mr. Chairman.

Chairman OWENS. Thank you.

Mr. Fifield, your Careers Demonstration Training Program fascinated me, but your comments were a little frightening in terms of the cultural lag here, where technology has sort of run off and left the individuals who are able to deal with it to train people and teach people.

These 16 people—do you have them in a program? Are they still in the program?

Mr. FIFIELD. They are still in the program. They started last fall. They will finish up in 6 weeks. This is a full-year course of 15 hours a week of training. These are seniors, in their senior year in engineering, computer science, communicative disorders, industrial technology.

Chairman OWENS. Would you care to comment on my question about manufacturers and the possibility of establishing an industry here where the production of these kinds of devices might have a worldwide market. Is this something that ought to be looked at?

Mr. FIFIELD. I was fascinated by that question. I had not even thought of it before. Since you asked that question, my mind has been conjugating, trying to think of where our technology comes from, and I believe a lot of it does come from Japan and other countries. Particularly, that is true in a lot of the computer industries, in a lot of the components and so forth. I think that you bring up an issue that really does need to be looked at.

In 1986, there was a provision in the Rehabilitation Act that called for the development of orphan technology. This was designed to address this very problem; to start looking at the type of technology that is needed for small numbers of people that is not big enough for a business to invest in, like our orphan drugs.

Perhaps something along that nature needs to be reexamined. A lot more could be done in certain areas, but there will never be, with the number of people that will be able to afford it, a big enough market to expect a huge amount of investment from some companies; but, I think we have a parallel.

Chairman OWENS. In the world, you do not think there would be a big enough market?

Mr. FIFIELD. When we are talking about the world and we can start getting some return from some of the countries that have not been able to use technology in the past, then we may be looking at another possibility there.

Chairman OWENS. Maybe the government can play a major role in the development of these devices and do something different,

like charge a royalty for people who develop them themselves and then profit from them, so that there is some return that can go into the public coffers to be used to the benefit of people that need help the most.

Mr. FIFIELD. Nothing would make me more proud of America than to be able to export assistive technology rather than weapons. I think that if we could switch this around and starting leading out in that field, we would have a sense of pride and a sense of economic accomplishment that would be so much more beneficial.

Chairman OWENS. Your demonstration program will have 16 young minds, one of which might be able to take something like this and run with it.

What did you mean by the National Science Foundation competition that you enter into? I did not quite understand what that was about.

Mr. FIFIELD. That is a good question. Each year, the National Science Foundation has a competition in which you can submit—it is usually in the area of computers—different technology that is available, assistive technology, to help persons with disabilities, and then the award—I believe the total prize—the first prize is \$10,000—goes to the group that wins that. Each year they have from 40 to 50 different devices that go into that National Science competition, and so, we are putting two into that.

Also, in addition to the National Science, another one that I want to mention is the Easter Seals competition, which is not near as lucrative, but it gets a lot more interest in terms of devices. I believe we have found that there are a number of other corporations and companies that have competitions.

They are usually more of a prestigious nature rather than a lucrative nature. This is another project that some private foundation could really do something with that could make a difference for these young minds that you are referring to.

Chairman OWENS. Mr. Odum, this information about the competitions would be available on ABLEDATA?

Mr. ODUM. That would actually be under NARIC, but I know of a couple of them.

Chairman OWENS. It is under NARIC.

Would you say, Mr. Fifield, that your problem in finding people who are familiar with and who can teach assistive technology is peculiar to Utah, because Utah is a small State, or is this a national problem?

Mr. FIFIELD. My only data on that, Congressman, is my discussions with other technical grant project staff. It is a national problem. I do not believe it is at all unique to Utah.

I think some universities have further developed programs in areas close to assistive technology.

If they have a rehabilitation engineering center or an R&T center, which we do not have in Utah, I think that they would be more likely to have a few people. I think it is a national problem of frightening proportions, because I believe that we cannot teach our special educators or our communication disorders people enough about technology when the faculty members are afraid of it. That is precisely what we found: faculty members at universities that were not using the technology, did not name it, did not know what

ABLEDATA was, did not want to get into the area because they were——

Chairman OWENS. Technophobic is the word you used.

Mr. FIFIELD. They were all tenured, sir.

Chairman OWENS. Mr. Odum, would our databases show that the people across the Nation are in greater abundance than in Utah?

Mr. ODUM. No, I do not think so. I think Utah is very typical.

Chairman OWENS. A database dealing with training and——

Mr. ODUM. Yes.

Chairman OWENS. [continuing] expertise in——

Mr. ODUM. It does not deal—as a major focus on training. There is another database out of Oklahoma State University on training materials that would have more specifics. We are in close contact with them all the time, and we would refer out that way.

Chairman OWENS. Would you care to comment, Mr. Yajnik?

Mr. YAJNIK. There are certain universities that are offering these programs. However, they are not graduating any numbers that we can be proud of, and I think training is a major deficiency.

I would like to address that, since you mentioned that you are a librarian. When you are talking about databases and information systems, librarians are very good in terms of classifying lots of information, digging out obscure facts, literature, and even sometimes rare services.

So, I have approached, in terms of training, some of the library schools to see if they would offer training for information referral specialists. While this is a specialized area, they do not have skills or the faculty to teach these people, and that is where, I would say, if there is a group of—let us say, an interdisciplinary program between engineering, computer science, library science, and even, to a certain degree, medicine—that would provide good all-around training for students.

Chairman OWENS. While you are at the mike, Mr. Yajnik——

Mr. ODUM. May I add to that very quickly, because I have two experiences.

Both the Catholic University of America and Maryland University offer graduate courses on providing services to people with disabilities—the classes actually come out and visit both NARIC and ABLEDATA.

We are lucky, because the teachers of those classes, at one time or another, did work for NARIC or for ABLEDATA. So, it does happen, but it is just—it is so small, but I think that those are models.

The ALA is very accepting of these things, but again they realize it is a tiny piece of information in that whole world of information.

Chairman OWENS. Mr. Yajnik, with reference to your proposal for an I&R national network, based on your study, would you care to comment on Mr. Odum's comment about the smallness of your sampling and how that impacts upon your recommendations?

Mr. YAJNIK. We talked about that informally, about the smallness of our sample. What he was referring to was that there are so many people out there with so many diverse, I guess, needs as well as disabilities; how can you identify these people?

We sought help from faculty of our university, from the Department of Statistics, to identify a representative sample.

In this way, if there are 45 million people, you do not have to get 40,000 people to get a good insight into what they may be saying.

If you are able to obtain a representative sample, even a small sample, the confidence level may not be as great. If you have a larger sample, of course your confidence level is that much more.

However, with the scope of the study and the timeframe that we had to obtain the responses, we obtained the license tags and the information on people with disabilities from the motor vehicles department from 10 States and that formed one portion of the informants that we surveyed, along with many others.

So, we feel quite confident that, even though it may appear that the sample that we have was small, the information that we have derived from that is fairly representative of how people feel.

Chairman OWENS. You said that a national network is not only desirable and needed but also feasible. Would you like to explain a little more about what you mean by feasible? Do you mean you can do it with a good cost-benefits ratio? What kind of cost are we talking about?

Mr. YAJNIK. Absolutely. Well, there are so many things that we have recommended, and the information and referral program—you cannot just do one thing and assume that it will work all together.

There are good programs available. What needs to be done is to form a cohesive network that supports the ongoing and existing efforts already in place, so that energy is not wasted in reinventing the wheel, avoiding the pitfalls that most people would encounter if they are doing it on their own, not knowing which way to go.

This field is fairly new, and what we are suggesting—what is feasible is to take what is there, start building a network so that we are providing a framework within which various programs can evolve and remain responsive to the people who need it.

For example, one of the things that NARIC does well is provide information about assistive technology and rehabilitation. However, if you ask Mark, he would say the calls that they get are not limited to rehabilitation information. They come from all over the place, asking for all kinds of things.

Now, they may or may not have that information, and their ability to manage that kind of information also would be fairly limited. Therefore, it would be useful to enlist the help of some of the other information programs that may be out there. Creating such linkages is essential to maximize the dollars that are being spent.

Chairman OWENS. The figure of \$6.5 million was included in your report as the approximate cost.

Mr. YAJNIK. That is if you would indulge in all of the initiatives that we have proposed. We have proposed those initiatives along a timetable in steps. You do not have to do everything at one time, but that is what it would cost, over time, to do everything correctly. For example, public—

Chairman OWENS. Six and a half million dollars is not an annual cost.

Mr. YAJNIK. That is correct, sir.

Chairman OWENS. Over 5 years, you could create a system which is ideal for \$6.5 million.

Mr. YAJNIK. That is correct.

Chairman OWENS. You would build on what exists already?

Mr. YAJNIK. Yes. Right in the beginning, you can have a program that starts building these linkages, starts building the structure or the framework within which all these programs can work with each other and then identify what is still not there and develop that.

Chairman OWENS. This would just be for assistive technology—

Mr. YAJNIK. Yes.

Chairman OWENS. [continuing] or for disabilities in general?

Mr. YAJNIK. This will be in assistive technologies, building upon the other programs that are out there.

For example, the NICHY program that caters to the need for information related to education, the aging programs that are out there. They are already funded. I am not saying that we seek help from them, but what I am saying is if we have to do it within the rehabilitation and the assistive technology information, then that is what it would cost.

Chairman OWENS. Do you care to comment on that, Mr. Odum?

Mr. ODUM. Which portion of that?

Chairman OWENS. The cost.

Mr. ODUM. The cost. His low point is \$6.5 million. You said something about a perfect system.

Chairman OWENS. State of the art.

Mr. ODUM. State of the art. I think we are looking into a crystal ball. We are seeing information grow at exciting levels, unbelievable levels.

I do not know if any of us here in this room could even estimate the amount of information that is going to be generated and able to be collected and disseminated 5 years from now. So, to say it is state of the art and say it is going to be a panacea might be more of a wish.

I think that it is going to take a lot of funding all the way down the line. Even if funded at the maximum of \$10 million for 5 years, I do not know if that is going to be enough.

Chairman OWENS. You would agree we have to do something to get beyond these busy 800 numbers?

Mr. ODUM. Yes, indeed.

Chairman OWENS. That is a constant complaint we get, that the 800 numbers are always busy.

Mr. ODUM. Well, one of the nice things I receive with my bill is a breakout of how many—what is it?—uncompleted calls, which are busy calls. I wish I had the percentage. I do not think it is 30 percent, but there are a fair amount of uncompleted calls.

Chairman OWENS. Well, I want to thank you, gentlemen. We have learned quite a bit. In the next 10 days, we may be in touch with you for some additional questions, and please feel free to submit any additional recommendations to us within the next 10 days.

We found this very useful, and I hope that you will talk to each other while you are here. I think there is valuable information you could share with each other.

Thank you. The hearing is now adjourned.

[Whereupon, at 1:33 p.m., the subcommittee was adjourned.]

[Additional material submitted for the record follows:]

STATEMENT OF KATHY E. VESLEY, ACTING DIRECTOR, COMMONWEALTH OF VIRGINIA,
DEPARTMENT FOR THE DEAF AND HARD OF HEARING, RICHMOND, VIRGINIA

As Acting Director of the Virginia Department for the Deaf and Hard of Hearing, I would like to take this opportunity to welcome you and the Congressional Subcommittee on Assistive Technology to Richmond for your public hearing on the continuation of funding under the Assistive Technology Act.

VDDHH has been an active supporter of the activities of the Virginia Assistive Technology System [VATS] through involvement with the advisory council of that office. Further, the agency has been the beneficiary of funding through the VATS grant process. I am pleased to report to you that more than 700 individuals have received training through Project TAPE, a train-the-trainer program which provides a comprehensive notebook on various assistive technologies available to improve the quality of life of persons who are deaf or hard of hearing. This program has been targeted to older Virginians who often experience frustration when everyday tools of communication such as the television and telephone are no longer easily accessible. The package will be updated on regular intervals as an important component of our Technology Programs.

In addition, VDDHH has recently received funding from VATS to conduct several activities in conjunction with a legislatively mandated study on the barriers faced by persons with sensory disabilities in emergency and law enforcement situations. The department anticipates completing a survey of 911 and other emergency phone services, developing a pocket handbook for emergency personnel, developing a best practices guide, and implementing a consumer education plan to increase the awareness of persons who are deaf, hard of hearing, or blind in emergency situations. In all cases, the availability of assistive technology will be a keystone to the products developed.

VDDHH is committed to improving both the availability of and the awareness about assistive technology for persons with sensory disabilities. This may only be achieved through reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act of 1988. I urge you to continue your efforts to ensure this reauthorization. Please let me know if I may be of further assistance.



COMMONWEALTH of VIRGINIA

THELMA E. BLAND
COMMISSIONER

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April 19, 1993

The Honorable Robert C. Scott
The Jackson Center
501 North Second Street
Richmond, Virginia 23219

Dear Congressman Scott:

On behalf of thousands of older Virginians who need and use assistive technology, we welcome you, Congressman Owens, and your staff members to Richmond. Assistive technology is extremely important for older people, as well as, younger people with disabilities in maintaining dignity, independence, and personal autonomy.

Today the hearing is being attended by representatives of the following area agencies on aging:

- Jefferson Area Board for Aging, Inc. -
Charlottesville
- Peninsula Agency on Aging, Inc. -
Newport News
- Crater District Area Agency on Aging, Inc. -
Petersburg
- Capital Area Agency on Aging, Inc.
Richmond

Although your schedule may not permit time for them to speak, I want you and the subcommittees to know how vital the Tech Act is in the lives of all people with physical limitations. We urge you to work hard for its reauthorization.

Thank you again for coming to Richmond. I will be glad to provide the subcommittee with any additional information you need from the perspective of older persons.

Sincerely,

Thelma E. Bland

TEB/me

An Equal Opportunity Employer



JEFFERSON AREA BOARD FOR AGING
 2400 Commonwealth Drive, Suite H-1
 Charlottesville, Virginia
 22904
 804 277-5222
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APR 26 1993

Your Agency on Aging Serving the Citizens of Charlottesville, Albemarle, Fluvanna, Greene, Louisa and Nelson

Board of Directors

Albemarle:
 Edward Jones, Chair
 Virginia Lee
 John K. Plante
 Mark Reister

Charlottesville:
 Robert Boucheron
 David C. Carter
 Mary K. Williams

Fluvanna:
 Angella Husted
 Roland Watts

Greene:
 Lee Esley
 Mary O. Holden

Louisa:
 Margaret Franklin
 Audrey Johnson

Nelson:
 Sara C. Burnet
 T. Carson Hefler

Executive Director:
 Gordon Walker

April 23, 1993

**The Honorable Robert C. Scott
 The Jackson Center
 501 North Second Street
 Richmond VA 23219**

Dear Congressman Scott:

The Jefferson Area Board for Aging (JABA), part of Virginia's aging network, appreciates the way you and Congressman Owens took the time to hear the voices of professionals and consumers who need and use assistive technology. This letter reiterates Department for the Aging Commissioner Bland's emphasis on the need for enhanced programs and service to older Virginians.

To demonstrate the utility of home safety and assistive technology of how our agency has been successful implementing programs through the support of local government and private funding.

- During the last six months, JABA served 103 older adults through "low-tech" Assistive Technology devices and adjustments to individuals' homes.
- Demographically, 34% of the persons served were over the age of 80, while 33% were 71-80. The ability of these persons to move about, as assessed by an O.T., found 50% to be independent, and 40% could ambulate with the assistance of a walker or a cane.
- Finally, JABA worked with its case managers and other program staff to receive 36% of the referrals for the program. Other significant referral sources included 17% from Departments of Social Services, 20% from Home Care/Hospice, and 5% from Housing Improvement Programs.

These seniors needed very basic and inexpensive adjustments to their homes. JABA suggests this investment be made to delay or even prevent the expensive option of institutionalization.

A recent GAO Study has stated how programs like ours can keep people at home and reduce home care costs. There is a need, however, to expand access to these low-cost, yet essential services.

Celebrating 18 Years of Community Service to the Elderly and Their Families

Hon. Robert C. Scott

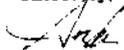
- 2 -

April 23, 1993

Two potential solutions would be to allow Medicare Parts A & B to fund these AT devices, to serve as follow through on the OT environmental assessment that Medicare does fund. Also, Medicaid, a budget which is still heavily burdened with the cost of institutional care, could give the option to localities to purchase and install AT devices through the community based waiver program.

These suggestions are even more paramount after reviewing testimony from Mary Somoza and the challenges her family faces with disabled children. If an effort can be made to keep our elderly out of institutions, then these program dollars can be freed up to assist persons of all ages in need of assistive technology.

Sincerely,



Gordon Walker
Executive Director

mn

pc: Comm. Thelma Bland
Chris Pruett, Director DMAS Community Waiver Program



**THE IOWA PROGRAM FOR
ASSISTIVE TECHNOLOGY**

May 7, 1993

The Honorable Major Owens, Chairperson
Subcommittee on Select Education
and Civil Rights
U.S. House of Representatives
O'Neil Building
Washington, D.C. 20515

Iowa University Affiliated Program
University Hospital School
Iowa City, Iowa 52242 1011

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Re: Reauthorization of P.L. 100-407, The Technology-Related Assistance for
Individuals with Disabilities Act of 1988, with special reference to enhancing
legal advocacy for persons who use assistive technology

Dear Representative Owens:

We are honored and pleased to respond to your request for a review of the issues that the Iowa Program for Assistive Technology (IPAT) has considered in determining the most effective ways to meet the needs for advocacy of Iowans with disabilities and their family members (consumers) for obtaining assistive technology and assistive technology services. We believe that addressing these advocacy issues are critically important to ensure that the technology needs of Iowa's consumers are met. Consequently, as Iowa's state grant program that is authorized by Title I, P.L. 100-407, IPAT holds increasing such advocacy as one of its highest priorities. We appreciate the opportunity to describe the factors, which may or may not be unique to our state, that affected our decision making in this regard.

The text that follows will begin with a description of the advocacy needs that were initially identified by our Program, the advocacy needs that are presently being addressed in the Program's activities, and those needs that continue to require resolution which relate primarily to legal advocacy. The second section will outline the factors that were identified as important in determining the best resources available to meet these unmet legal advocacy needs of consumers in Iowa. The final section summarizes the reasons our Program chose to utilize the resources at the Legal Clinic at the University of Iowa College of Law as a primary vehicle for meeting these unmet needs.

Advocacy Needed For Systems Change

Our Program is addressing two primary levels of advocacy that are essential to accomplish "systems change" to bring about a statewide consumer responsive program of assistive technology services. One of these levels of advocacy calls for working within the present public-private system of assistive technology services, and the other level is outside that system.

Advocacy within the system is being generated to enhance the recognition of state policy makers, state agencies, and service providers for needed change. Our Program is working to establish that recognition, and the involved entities are

THE IOWA COUNCIL ON ASSISTIVE TECHNOLOGY

Assistive Technology Users • Iowa Rehabilitation Technology Alliance • Iowa Coalition for Persons with Disabilities • Iowa Commission of Persons with Disabilities
Governor's Planning Council for Developmental Disabilities • Great Services Commission of Iowa • Iowa Transition Initiative • Creative Employment Options of Iowa
Iowa State Association of Counties • Iowa's Area Education Agencies • Iowa Department for the Blind
Bureau of Special Education and Division of Vocational Rehabilitation of the Iowa Department of Education
Iowa Department of Elder Affairs • Iowa Department of Human Services • Iowa Department of Personnel • Iowa Department of Public Health

beginning to work to change the present service delivery system so that it will be responsive to the needs of consumers and, hence, bring to fruition the model articulated in the Technology Related Assistance for Individuals with Disabilities Act (the Act).

The other level of advocacy we are working to develop is that which must be undertaken by consumers of assistive technology and their family members. These consumers must not only advocate for their own technology needs, but they must further advocate to become partners in shaping the new service system. When advocating for their own technology needs, consumers also must frequently decide whether to pursue a review of a decision to deny funding for assistive technology through an appeal process. These consumers and their family members often need a legal advocate to help them successfully pursue such an appeal.

Advocacy Needs Being Addressed in Ongoing Activities

Our Program has ongoing activities that are designed to meet the advocacy needs described above. Advocacy within the system is facilitated through formal training and information distribution to service providers and state agency personnel. These activities are designed and conducted in consultation with six Work Groups that deal with the areas of funding, awareness, training, service delivery, transportation and environmental access. Each work group is comprised of consumers, service providers, representatives from state agencies, and other appropriate entities (e.g., representatives from third party payers on the Funding Work Group). The Iowa Council for Assistive Technology (ICAT), IPAT's advisory board, is comprised of consumers, family members, representatives of advocacy groups, service providers, and state agency directors. ICAT provides oversight of Program activities and the development of a state plan for assistive technology services. Also, that Council provides a forum for consumers, advocacy groups, and state agency heads to discuss critical issues needed to formulate new policies, procedures, and practices. The consumer membership of the Work Groups and Council promotes their advocacy throughout all aspects of the Program's activities.

Increasing the expertise of consumers and family members in advocating for assistive technology has become a focus area of our Program's activities. This focus is due to our determining that, philosophically, informed and empowered consumers ensure ongoing systems change and, pragmatically, many consumers in Iowa lack effective advocacy skills.¹

Consumer training (for consumers of assistive technology and their family members) has been developed in the areas of self-advocacy, funding, and "consumerism". A consumer consultant has worked on developing each training module. The training modules are complimentary. The self-advocacy training is

¹ The Iowa Program for Assistive Technology commissioned a study of acquisition barriers for Iowans in obtaining assistive technology. Consumers involved in the study reported that they were unable to articulate their technology needs in an effective manner to programs and agencies. See, Institute for Social and Economic Development, "Acquisition Barriers: Assistive Technology and Iowans with Disabilities", pp. 39-40, 1992, available upon request.

designed to build skills in independent decision making and articulation of technology needs. The training relative to acquiring funding provides information and techniques for approaching agencies in obtaining funding for purchase of assistive technology and assistive technology services. The consumer training also provides information about consumer rights and responsibilities when purchasing equipment, equipment warranties, and equipment maintenance.

IPAT has sponsored Consumer Forums in six Iowa communities during each of its first three years of programming, and nine of these Consumer Forums will be conducted in each of the next two years. Local consumer groups in each community cosponsor the Forums, which are open to the public, and decide the format and theme. Before each Forum, our consumer consultant travels to the Forum site and trains local area consumers to provide the training modules to be conducted. This "train the trainer" model works to give consumers greater access to information and promotes the concept of consumers as experts relative to their needs. IPAT also helps to provide state and regional speakers for the Forums, such as regional consultants on issues related to the Americans With Disabilities Act and an Iowa Assistant Attorney General to speak on consumer protection issues.

Consumer training will expand over the next two years. This expansion will be initiated by a statewide training and leadership conference. This conference, to be held in October of this year, will be the first in Iowa to be planned by consumers with nationally recognized consumer speakers and with most conference presenters being consumers. IPAT has received support from advocacy groups, agencies, and other grant programs for this conference. Consumers and family members identified as advocacy leaders by groups such as Iowa Governor's Planning Council for Developmental Disabilities, the Iowa Protection and Advocacy, the Iowa Creative Employment Options, and the Iowa Transition Initiative will be invited to participate in the conference.

The training presented at this conference will increase the expertise of our present consumer trainers with respect to assistive technology issues and advocacy. It will also increase the number of trainers and peer advocates available in local areas of the state. Most importantly, this conference will serve to demonstrate to consumers throughout Iowa their role in bringing about the needed systems change.

Also, IPAT will begin a new training program this year aimed at reaching members of minority groups who have disabilities. It is also a "train the trainer" model, designed to train members of minority communities about assistive technology and advocacy issues. These "trainers" will then be assisted in providing training in their local communities.

Unmet Legal Advocacy Needs

The study described above in Footnote 1 also identified two related barriers faced by consumers in Iowa. The first barrier is the lack of expertise on the part of consumers to effectively challenge decisions which deny funding for assistive technology by going through an appeal process. The second is to find effective legal representation in the state relative to assistive technology issues. Finding effective

legal advocacy can be particularly difficult for the underserved populations² in our state. In addition, effective advocacy representation would eliminate the burden on consumers and their families to have the requisite skills necessary to successfully navigate the appeal process.

Factors in Determining How to Meet Needs for Legal Advocacy

It has become apparent that our Program must work to increase the availability of expert legal advocacy for consumers. In determining how to proceed to effect that increase, we considered the following issues: 1) serving all Iowa consumers of assistive technology, including the identified underserved populations of elderly (including the frail elderly), farmers with disabilities, and minority groups; 2) serving Iowa consumers in a manner that promotes the system change philosophy of the Act and our Program; and 3) increasing consumer choice through self-determination.

Among the options considered were contracting with the Iowa Protection and Advocacy Agency, the Law Clinic at Drake University, and the Legal Clinic at the University of Iowa College of Law to provide the needed legal services to consumers. Our Program decided to contract with the entity that expressed the strongest desire to work with us and that could best meet the above criteria in providing legal advocacy. The program at Drake University has not expressed sufficiently strong interest.

1. Underserved Populations

The population profile of Iowa shows a state with an ever increasing aging population. Iowa leads the nation in the proportion of "frail elderly" - that portion of the aging population most in need of assistive technology to remain independent. This population as a whole is not served by the Protection and Advocacy Agency in our state. Iowa Protection and Advocacy has been limited to issues arising from an individual's developmental disability or mental illness.³

² Iowa has a large proportion of its population who are elderly and, in particular, "frail" elderly (i.e., those most in need of assistive technology). In a 1991, IPAT undertook a needs assessment of the elderly population in Iowa. 18% of the community dwelling elderly, (i.e., nonfarm residents), interviewed indicated they had at least one activity of daily living that they could not perform without assistance. Over half of those did not have assistive technology, but rather relied on another individual to help them perform that daily living task. The elderly have been identified as one population "underserved" with respect to assistive technology in Iowa.

Two other populations have been targeted as underserved because of lack of access to these services. Iowa, like other farming states, has a substantial number of farmers and farm family members who become disabled in farming accidents each year. The lack of services in rural areas and the "tradition" of not seeking outside assistance contributes to the underutilization of assistive technology by this group.

The third underserved population are the minority groups in Iowa - African-American, Hispanic, Latino, Asian Americans, and especially Native Americans. Because these groups are underserved by medical and health professionals, they are most likely underserved with respect to assistive technology.

³ "Iowa Protection and Advocacy News", Vol. 6, No. 3, Fall, 1992, p. 6.

Similarly, farmers who become disabled as a result of farming accidents have not been served by Iowa's Protection and Advocacy Agency unless they also have a developmental disability or mental illness. The same is true for members of minority groups with disabilities - the disability must be a developmental disability or mental illness in order to have received services from Protection and Advocacy.

Since the Protection and Advocacy Agency in Iowa does not have a mandate to serve these populations, and doing so has not been within its priorities, the Agency does not have experience in working with them. More importantly, the likelihood of the Agency being able to provide services to these populations after our Program terminates seems minimal. As described below, our Program has maintained that activities it supports must show strong potential for continuing after our grant expires. Otherwise, we will not be fulfilling our obligation to effect permanent systems change.

The Legal Clinic at the University of Iowa College of Law⁴ received a grant in 1987 to fund a Farm Law Project to address the agricultural crisis then occurring in the state. The Clinic received external financial support to fund the project until 1992. Despite the loss of external funds, the Clinic is continuing its Farm Law Project in part because of a recognition that legal assistance to family farm operations is a permanent need in the state. Therefore, not only does the Clinic have experience and credibility in the rural communities in Iowa, it has the potential to continue programs after the end of a grant period.

The Clinic also has received grants from the Iowa Office of Elder Affairs to fund an Elder Law Project. In addition, the Clinic has had close ties with the Tama Indian legal services project⁵ and the faculty at the College of Law includes two leading Native American Law experts, Robert Clinton and S. James Anaya.

2. Systems Change

Another factor considered by our Program was the likelihood of ongoing systems change resulting from the way in which legal advocacy services were contracted. Providing services through the Law Clinic ensures that law students will receive training in representing individuals with disabilities to obtain assistive technology.⁶ This was a very important consideration. Increasing the potential pool

4 The Clinical Law Program at the University of Iowa College of Law has grown considerably from two faculty members staffing an in-house live client Prisoner Assistance Clinic in 1972. It is currently staffed by seven full time clinical faculty, and the Clinic has taken on several individual projects, such as the Civil Litigation Project, which for several years included funding from the Iowa Protection and Advocacy Agency, the Farm Law Project, Administrative Law Project, Aids Project, Immigration Law Project, Elder Law Project, and Criminal Defense Project. The Clinic is now organized more like a single law firm, with departments such as civil rights and liberties, employment, general civil, criminal defense, wills and trusts, family law and so forth. Faculty members work in their areas of expertise and interest.

Between 100 and 120 students enroll in the Clinical Law Program a year (fall, spring and summer semesters). The Clinic has litigated all levels of cases - administrative hearings, state district, appellate, and supreme court, federal district, appellate and United States Supreme Court.

5 Professor Clinton supervised clinical students who participated in the Tama project to provide legal services to members of the Tama tribe.

of attorneys willing and able to represent persons with disabilities facilitates their ongoing access to the legal system.

As mentioned above, the Clinic has demonstrated the ability to continue the representation of underserved populations after the expiration of grant funding. Short term funding of services creates expectations which cannot be met over the long term.

3. *Consumer Choice*

The process of educating law students in this area of advocacy creates the potential for more legal advocates available statewide to represent persons with disabilities. This representation can occur whether these students will choose to work in the public interest sector or in the private sector. The Iowa Bar has an active volunteer lawyer project where private attorneys provide pro bono legal services. Hence, all consumers are likely to have available these services in future years.

The increased availability of legal advocates creates more choices for persons with disabilities. Consumer choice is a fundamental part of a consumer responsive system of services. Consumer choice also creates greater independence for persons with disabilities and their families.

Summary

The Iowa Program for Assistive Technology determined that, based on the factors described above, that contracting with the Legal Clinic of the University of Iowa College of Law for legal advocacy was in the best interests of consumers in Iowa who need legal advocacy in their quest for assistive technology. That is, it was determined that the Legal Clinic had more experience and expertise in representing the populations in Iowa that are underserved relative to assistive technology services, and the opportunity for educating law students in this area of the law promotes ongoing systems change. The Legal Clinic has demonstrated an ability to continue representation of underserved populations when external funding of a project has expired, which also will provide an ongoing source of assistance to Iowa's consumers. Finally, increasing the availability of legal advocates through law school training increases consumer choice and independence.

⁶ The Legal Clinic and the Iowa Protection and Advocacy Agency have a close ongoing relationship. Iowa Protection and Advocacy contracted for the services of Carroll Lucht, the director of the Civil Litigation Clinic, for many years. Professor Lucht left Iowa for a position at the Yale Law School Clinic. Since his departure the two entities have a relationship which provides space at the Clinic for one of the two Protection & Advocacy attorneys. One clinic student per semester can work in an externship with the Protection & Advocacy attorney.

The clinical professor who will direct this project, John Allen, is able to supervise several students per semester for the contracted Assistive Technology Project.

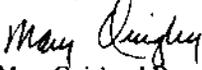
Recommendations

We are aware of the issues, and considerations being given, to ensure that the state grants that are authorized by Title I, P.L. 100-407, appropriately fulfill their responsibility for increasing consumer advocacy relative to assistive technology and assistive technology services. We can support a requirement that the state grants must undertake such activities in changes that may be made upon the law's reauthorization.

However, a major reason for the success we are realizing here in Iowa to enhance the development of a consumer responsive statewide assistive technology service system is the flexibility provided by the current statute. That is, Title I of the Technology-Related Assistance to Individuals with Disabilities Act of 1988 permits exceptional flexibility in the manner with which each state can work to achieve needed goals. Therefore, we strongly recommend that this flexibility be retained by not requiring the state grant programs to meet a specific need in a specified manner, including the manner in which consumer advocacy is to be enhanced. Doing so may require a state to proceed in ways that are not optimum due to the contingencies within that state.

Again, we deeply appreciate having had the opportunity to provide you with the above information and considerations. We will be pleased to respond to any comments or questions you may have.

Sincerely yours,



Mary Quigley, J.D.
Program Specialist


James C. Hardy, Ph.D.
Director